Broken Promises:

Evaluating the Native American Health Care System

September 2004

U.S. Commission on Civil Rights

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- Study and collect information relating to discrimination or a denial of equal protection of the laws under the Constitution because of race, color, religion, sex, age, disability, or national origin, or in the administration of justice.
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Letter of Transmittal

The President
The President of the Senate
The Speaker of the House of Representatives

Sirs:

The United States Commission on Civil Rights transmits this report, *Broken Promises: Evaluating the Native American Health Care System*, pursuant to Public Law 103-419.

It has long been recognized that Native Americans are dying of diabetes, alcoholism, tuberculosis, suicide, and other health conditions at shocking rates. Beyond disturbingly high mortality rates, Native Americans also suffer a significantly lower health status and disproportionate rates of disease compared with all other Americans. Finding disparities in the health status and outcomes for Native Americans, the Commission explored the causes for those disparities. Consequently, the Commission report assesses whether the Indian Health Service (IHS), and the Centers for Medicare and Medicaid Services (CMS) are improving the delivery of health services and the overall health status of Native Americans. In essence, this report evaluates the Native American Health Care system.

Based on a Commission briefing, interviews, research, and a review of relevant literature, the report concludes that our nation's lengthy history of failing to keep its promises to Native Americans includes the failure of Congress to provide the resources necessary to create and maintain an effective health care system for Native Americans. The Commission's report documents the existence of cultural, social and structural barriers that continue to limit Native American access to health care. These barriers must be removed. Accordingly, the Commission makes numerous recommendations including educating and training health care providers on cultural differences that influence the effectiveness of disease prevention and treatment programs, recruiting more health care providers to reduce patient wait times and ensure that services are available when needed, increasing the retention rates for IHS health care providers to improve the continuity of health care and strengthen the doctor-patient relationship, improving program monitoring and evaluation, modernizing data collection, increasing appropriated funding levels, increasing enrollment in public insurance programs, and increasing collections from third party insurers. The recommendations also call for expedited passage of pending legislation intended to improve Native American access to health care.

The report also reveals that the Native American health care system created by the federal government has used only limited and incremental responses to the health care challenges faced by Native Americans. Specifically, the Commission has found that, although IHS has, in many cases, identified solutions to the health problems so common in Indian Country, Congress has failed to provide the resources necessary to implement those solutions. The Commission believes that the current Native American health care system requires the rapid implementation of the remedial measures identified in this report.

This report compels the federal government to acknowledge the dire health care situation facing Native Americans. A long history of treaties and broken promises urges the federal government

to recognize that the concept of fulfilling treaty promises through proper funding and effective administration is a moral imperative. The federal government must take immediate action to improve the health status of Native Americans.

For the Commissioners,

Mary Frances Berry

Chairperson

Acknowledgments

The Commission briefing was organized and the report written by the Office of General Counsel, under the supervision of Deputy General Counsel Debra A. Carr. Attorney-advisors Jenny Kim Park, Deborah Reid, John Blakeley, and Barbara de La Viez* performed preliminary research and planning for the briefing. Office of General Counsel secretary Pam Moye** provided clerical support for the briefing.

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Introduction

> *If you're a young Lakota woman with a big heart, an even bigger smile, but an immune system compromised to its brink by lupus—you know who the enemy is. If you're a tribal chairman receiving a phone call in the middle of the night that another one of your tribal members has taken their own life—you know who the enemy is. If you are a teacher, attempting to prepare tomorrow's leaders but knowing full well that a number of your students aren't capable of concentrating on school work because of alcohol related family problems—you know who the enemy is.*[1]

Today, in Indian Country, health-related problems and the lack of adequate health care are the enemy. This was borne out on October 17, 2003, when the U.S. Commission on Civil Rights (Commission) held a public briefing in Albuquerque, New Mexico, to examine the extent of the disparities in the health status and outcomes of Native Americans, and to explore the causes for those disparities.[2] Information gathered during this briefing is incorporated into this report. Also reflected in this report is information discovered during a survey of existing literature and studies on Native American health disparities, as well as interviews of tribal leaders, tribal members, policy analysts, researchers, care providers, and representatives of the Indian Health Service (IHS) and the Centers for Medicare and Medicaid Services (CMS).[3] In addition to conducting interviews of IHS and CMS leadership and staff, the Commission used interrogatories to obtain additional information about IHS and CMS policies and practices. Finally, members of the Commission staff gathered information during a tour of the Gallup

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[1] Collette Keith, "IHS Looks Toward an Epi Center to Tackle Health Disparities on the Great Plains," *The Native Voice*, vol. 1, December 2002, p. 1.

[2] Throughout this report, the term "Native American" is used in lieu of "American Indian" or other terminology when not specifically citing or paraphrasing other work. It should be understood to include Alaska Natives unless otherwise noted. Native Hawaiians are not included in the Native American category because they are not recognized as having the same government-to-government relationship, and are thus not eligible for the federal programs available to other Native groups. The term "Indian Country" refers to geographic regions encompassing reservations and trust lands within which Indian laws and customs and federal laws relating to Indians govern. *See* Theodore H. Haas, chief counsel, United States Indian Service, *The Indian and the Law* (Lawrence, KS: Haskell Institute, 1949), p. 15, <http://thorpe.ou.edu/cohen/tribalgovtpam2ptl&2.htm> (last accessed Nov. 21, 2003). It is also important to recognize that Native Americans are not simply another minority or ethnic group. They enjoy a unique political status that carries unique privileges discussed in more detail in this report.

[3] Members and representatives of several tribes and tribal advocates were interviewed or otherwise provided information during the course of the Commission's examination of Native American health care issues. Included among those providing information are the following: Cherokee Nation; Navajo Nation; Fallon Paiute Shoshone Tribe; Wampanoag Tribe; Shoshone Paiute Tribes of Duck Valley; Jamestown S'Klallam Tribe; Mille Lacs Band of Ojibwe; Choctaw Nation; Kaw Nation; Chippewa Cree Tribe; Lummi Nation; Hoopa Valley Tribe; Creek Nation; Oglala Sioux Tribe; Zuni Pueblo; Santo Domingo Tribe; Santa Clara Pueblo; Cochiti Pueblo; Poarch Creek Indians; Hopi; Taos Pueblo; United Tribe; San Carlos Apache Tribe; Ottawa Indian Nation; Dineh Nation; California Rural Indian Health Board; Northwest Portland Area Indian Health Board; National Indian Health Board; Alaska Native Tribal Health Consortium; Seattle Indian Health Board; Denver Indian Health and Family Services; National Indian Youth Council; Sonosky, Chambers, Sachse, Miller & Munson LLP; Hobbs, Strauss, Dean & Walker LLP; Association of American Indian Affairs; National Native American AIDS Prevention Center; American Indians in Texas; International Indian Treaty Council; Albuquerque Metro Native American Coalition; and Freedmen Descendants of the Civilized Tribes.

Indian Medical Center in New Mexico and an informal listening session with tribal members and others concerned about the state of the Native American health care system.

This fact-finding process resulted in the discovery of compelling evidence that disparities in the health status and outcomes of Native Americans persist four years after the Commission's 1999 report titled *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality*, and after many years of periodic reporting and monitoring of the health disparities experienced by Native Americans and people of color.

In Chapter 1, this report examines the nature and scope of documented Native American health disparities; it also provides an overview of the sources of the federal government's duty to provide health care to Native Americans. That duty derives from the special relationship between Native Americans and the federal government, a relationship resulting from "solemn obligations which have been entered into by the United States Government," and made specific by written treaties and informal agreements.[4] Chapter 1 explains why the federal government's responsibility to provide quality health care to Native Americans is inescapable and why that responsibility means raising the health status of all Native Americans.

It has long been recognized in Native American and medical communities that Native Americans are dying of diabetes, alcoholism, tuberculosis, suicide, unintentional injuries, and other health conditions at shocking rates. Beyond these mortality rates, Native Americans also suffer significantly lower health status and disproportionate rates of disease compared with all other Americans. These realities should come as no surprise to those with a basic knowledge of our nation's history and those charged with making policies that influence the future of the Native American population.

From the earliest days of colonization, the diseases brought from the Old World proved far more lethal than any weapon in the European arsenal. Infectious diseases, including measles, smallpox, and plague, among others, "annihilated entire communities even before they had seen a single European."[5] The toll taken by infectious disease, when combined with the effects of war, the expulsion of virtually all Native Americans from their ancestral lands, and the destruction of traditional Native American ways of life, effectively decimated the self-governance structures previously employed by Native Americans.[6] As a consequence, Native Americans became dependent on the federal government for the provision of adequate health care.

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[4] President Richard Nixon, "Special Message on Indian Affairs," *Public Papers of the Presidents of the United States: Richard Nixon, 1970*, pp. 564–67, 576.

[5] "Native Americans of North America," Encarta, <http://encarta.msn.com/encyclopedia_761570777/Native_Americans_of_North_America.html> (last accessed June 25, 2004).

[6] During the 400 years from the first appearance of European settlers to the start of the 20th century, a once-thriving Native American population was reduced to roughly 400,000. Estimates of the initial population range from more than 1 million to almost 18 million. *See* "Population: Precontact to the Present," Encyclopedia of the North American Indians, <http://college.hmco.com/history/readerscomp/naind/html/na_030500_precontacto.htm> (last accessed June 25, 2004). *See also* Resolution of Apology to Native American Peoples, S.J. Res. 37, 108th Cong. (2004), "this Nation should address the broken treaties and many of the more ill-conceived Federal policies that followed, such as extermination, termination, forced removal and relocation, the outlawing of traditional religions, and the destruction of sacred places." *Id.*

Shortly after the birth of our nation, the federal government became concerned with the health status of Native Americans. Initially, the motivation was based entirely on self-interest: the government needed to know how many Native Americans died from disease and to be able to estimate the size of the Native American population.[7] With the passage of time, however, the government's role became that of health care provider and the motivation shifted toward the fulfillment of an obligation. Nonetheless, federal efforts to provide adequate care were minimal. As early as 1926, the government formally questioned the adequacy of health care delivery to Native Americans. A 1928 report issued in response to this inquiry began a 76-year litany of government pronouncements that the existing health status of Native Americans was intolerable. Sadly, much of the substance of that 1928 report issued by the Meriam Commission remains true to this day. The report declared that:

> The health of the Indians as compared with that of the general population is bad. Although accurate mortality and morbidity statistics are commonly lacking, the existing evidence warrants the statement that both the general death rate and the infant mortality rate are high . . . The prevailing living conditions among the great majority of the Indians are conducive to the development and spread of disease. With comparatively few exceptions, the diet of the Indians is bad . . . The housing conditions are likewise conducive to bad health . . . The inadequacy of appropriations has prevented the development of an adequate system of public health administration and medical relief work for the Indians . . . The hospitals, sanatoria, and sanatorium schools maintained by the Service, despite a few exceptions, must be generally characterized as lacking in personnel, equipment, management, and design.[8]

A health care system matching this description requires the prompt implementation of effective remedial measures. This report updates a long series of studies and recommends appropriate measures for creating and maintaining an adequate health care system for Native Americans. Any study of the nature and scope of disparities in health status and outcomes, as described by the Meriam Commission and in subsequent reports, requires an examination of the system responsible for providing health care to Native Americans. During its examination of the IHS system, the Commission found that many of the disparities in health status and outcomes experienced by Native Americans result from social and cultural barriers. In Chapter 2, the Commission explores the roles of the most significant social and cultural barriers affecting Native American health:

- Racial and ethnic bias and discrimination.
- Patient health behaviors.
- Environmental factors.
- Delivery of health care in a culturally sensitive and appropriate manner.
- Language.

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[7] National Library of Medicine, "Early United States Government Interest in Native American Health," <http://www.nlm.nih. gov/exhibition/if_you_knew/if_you_knew_03.html> (last accessed July 15, 2003).

[8] Meriam Commission, "The Problem of Indian Administration" (Report of a Survey made at the request of the Honorable Hubert Work, Secretary of the Interior, and submitted to him, Feb. 21, 1928) Chapter I, <http://www.alaskool.org/native_ed/research_reports/IndianAdmin/Chapter1.html#chap1> (last accessed Feb. 3, 2004).

- Poverty.
- Education.

In its 1999 report on health disparities, the Commission found that racial and ethnic bias in health care systems manifests in a variety of ways, including differential delivery of health services; inability to access health services because of lack of financial resources, culturally incompetent providers, language barriers, and the unavailability of services; and exclusion from health-related research.[9] The ways in which racial and ethnic bias manifest and contribute to health disparities are as valid now as they were in 1999. Recent research reaffirms the Commission's findings: racial and ethnic bias, and stereotyping, continue to play significant roles in the quality of the physician-patient relationship and in access to medical treatment information.[10]

In addition to social and cultural barriers, the Commission determined that structural and financial barriers cause and contribute to health disparities. The structural barriers limiting access to care are discussed in Chapter 3 and include:

- Management or oversight issues relating to the different types of IHS services.
- Geographic location of facilities.
- Wait times at the facilities and for treatment.
- Age of facilities.
- Turnover rates of providers.
- Retention and recruitment of qualified health providers.
- Misdiagnosis or late diagnosis of disease.
- Rationing of health services.

The financial barriers are discussed in Chapter 4 and build upon the Commission's work in the 2003 report, *A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country*. The chapter focuses on the long-neglected and underfunded IHS, which inherited a system that historically has been deprived of the administrative, financial, and other resources necessary to

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[9] U.S. Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality*, September 1999, p. vii (hereafter cited as USCCR, *The Health Care Challenge*).

[10] *See* Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (National Academies Press, Washington, DC, 2002), p. 12:

> Finding 4-1: bias, stereotyping, prejudice, and clinical uncertainty on the part of healthcare providers may contribute to racial and ethnic disparities in healthcare. While indirect evidence from several lines of research supports this statement, a greater understanding of the prevalence and influence of these processes is needed and should be sought through research.

See also Karen Scott Collins et al., "The Commonwealth Fund—Diverse Communities, Common Concerns: Assessing Health Care Quality for Minority Americans," March 2002, <http://www.cmwf.org/programs/minority/collins_diversecommunities_523.pdf> (last accessed Feb. 9, 2004), and U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, *National Healthcare Disparities Report*, December 2003, p. 12.

provide health care equivalent to that provided to most other Americans. Twenty-one years after the Meriam Commission report first condemned the state of Indian health care, it was clear that any improvements in the health care provided to Native Americans were superficial. In 1949, the American Medical Association (AMA) railed against the lack of federal commitment to care for Native Americans, noting that recommendations presented to government officials were either not carried out at all or not executed beyond their initial stages because of inadequate funding.[11] Then, as now, experts called for Congress to increase funding. This chapter of the report discusses the many ways in which health care financing is inadequate.

Proposed legislative changes aimed at improving the delivery and quality of care provided are examined in Chapter 5. Legislation reauthorizing the Indian Health Care Improvement Act was introduced and debated in the past three sessions of Congress. These legislative efforts included extensive tribal consultation; the final version of the proposed reauthorization legislation received the full backing of tribal leaders, even though these leaders made many compromises. This chapter outlines the important provisions, including the sections deleted during negotiations, and how the proposed changes will affect health care.

Finally, in Chapter 6, this report makes recommendations for improving the delivery and quality of Native American health services. Several of the recommendations are rooted in increased funding, but this is not to exclude or underemphasize the value of significant reforms that can be implemented without sharp increases in IHS funding. Several recommendations focus on using existing resources wisely and adopting innovative approaches to disease prevention and detection. An example of a change requiring little or no increase in funding is a re-examination of how IHS teaches the value of preventive medicine and early detection. These concepts are uncommon in Native American communities. After careful examination, Dr. Linda Burhansstipanov, a member of the Western Cherokee Nation in Tahlequah, Oklahoma, concluded that for Native American adults prevention and detection is a low priority. Native Americans who are raised on reservations, or those with very traditional beliefs, value prevention and detection more when framed in the context of family and "bringing in a healthy next generation."[12] A woman will understand, for example, the value of an annual mammogram if she is told that early detection will allow her to survive to "teach her grandchildren the stories" of her people.[13] This same woman may not see the value of breast cancer screening if only told that it makes good medical sense. Likewise, teaching health care providers to be culturally aware and to demonstrate cultural sensitivity during the examination and treatment of Native American patients will increase the numbers taking advantage of available detection and intervention procedures. These changes, though not costly, would increase detection of many diseases that

[11] W.F. Braasch, B.J. Branton, and A.J. Chesley, "Medical Care Among the Upper Midwest Indians," *Journal of the American Medical Association*, January 1949, as cited in S. Rep. No. 94-1194, at 73 (1976), *reprinted in* 1976 U.S.C.C.A.N. 2711.

[12] Linda Burhansstipanov, "Leaders and Survivors," in *Eliminating Health Disparities: Conversations with American Indians and Alaska Natives*, eds. Michael E. Bird, William M. Kane, and Marcia Quackenbush (ETR Associates, 2002), pp. 37–38.

[13] Ibid., p. 38.

contribute to the decreased life expectancy of Native Americans and a diminished quality of life.[14]

Any specific effort to improve Native American health care will inevitably fall short of complete success unless certain principles and approaches are embraced. First, the extent of current health disparities in the Native American community and their relationship to historical events must be acknowledged by the federal government. Second, measurable long- and short-term goals designed to improve the health status and outcomes of Native Americans must be created and promptly implemented. These goals must encompass fiscal, legal, structural, and policy changes. Third, tribes must be provided expanded opportunities to control and manage the delivery of health care to Native Americans. The tribal leaders and the Native American people are up to the task of raising the health status of their own people. They desire control of their own destiny, yet they require congressional action to make their vision a reality. They require congressional action so that finally our nation will honor the commitments made so long ago. According to W. Ron Allen, chairman of the Jamestown S'Klallam Tribe, "if you authorize us, if you fund us, if you empower us, we can make the solutions a reality."[15]

This report, which examines the Native American health care system and the nature of historical relationship between tribes and the federal government, can be reduced to a single compelling observation: persistent discrimination and neglect continue to deprive Native Americans of a health system sufficient to provide health care equivalent to that provided to the vast majority of Americans. In a forum with tribal leaders, Senator Sam Brownback recognized this implicitly when he remarked that it is time to stop "poking the wound" of discriminatory treatment and to put equal efforts into "healing the wound."[16]

In this light, this report should be considered a clarion call to those who inexplicably fail to acknowledge the present state of Native American health care and to those who lack the commitment necessary to address the overwhelming need for clear and decisive action. Such a call is certainly appropriate for our political leadership and the message is clear—it is finally time to honor our nation's commitment to protecting the health of Native Americans.

[14] A Native American born in 2002 has a life expectancy of 70.6 years, compared with a life expectancy of 76.5 years for other Americans. *See* Indian Health Service, *Transitions 2002: A 5-Year Initiative to Restructure Indian Health*, October 2002, p. 9.

[15] Ibid. *See also* Ron Allen, chairman, Jamestown S'Klallam Tribe, telephone interview of Apr. 14, 2004.

[16] Jerry Reynolds, "Republican Forum Courts Native Views," *Indian Country Today*, Mar. 5, 2004, <http://www.indiancountry.com/?1078505241&style=printable> (last accessed Mar. 10, 2004).

Chapter 1: Nature, Scope, and Effect of Native American Health Disparities

Despite the creation of an independent public health system and more than $3 billion in funds appropriated by Congress each year to deliver health care services for Native Americans, a wide range of public health status indicators demonstrate that Native Americans continue to suffer disproportionately from a variety of illnesses and diseases.[1] In addition, Native Americans rate their health as fair or poor at a rate significantly higher than all other racial/ethnic groups.[2] Dr. Jon Perez, director of Behavioral Health for the Indian Health Service (IHS), described these health disparities as "real and highly visible" to Native Americans.[3] Poor health has become a community characteristic:

> [t]o people who live in such communities, these are not just numbers but the constant realities of sirens and phones calling them to hospitals and funerals. They must witness their favorite grandmother going blind or having her foot amputated because of diabetes or the high school basketball star moving to the city for diagnosis and treatment of AIDS because no one has the resources to deal with her.[4]

Consequently, not only is reduced health status a burden to Native Americans, but a cumulative drain on the entire Native American existence. Poor health inhibits the economic, educational, and social development of Native Americans and establishes an inescapable cycle of disparity. Nevertheless, not all news regarding health status is bad news. The IHS, which has been given primary responsibility for eliminating this disproportionate health status, has been largely successful in reducing mortality rates, while making significant improvements in other areas.[5] Dr. Perez explained that the incidence and prevalence of many infectious diseases have been dramatically reduced through increased clinical care and public health efforts such as vaccination for infectious diseases and the construction of sanitation facilities.[6]

Today, Native Americans continue to experience significant rates of diabetes, mental health disorders, cardiovascular disease, pneumonia, influenza, and injuries. Specifically, Native

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[1] *See generally* Office of Management and Budget, "Statistical Policy Directive No. 15: Race and Ethnic Standards for Federal Statistics and Administrative Reporting," 1977; Office of Management and Budget, "Recommendations from the Interagency Committee for the Review of the Racial and Ethnic Standards to the Office of Management and Budget Concerning Changes to the Standards for the Classification of Federal Data on Race and Ethnicity," July 9, 1997, <http://www.whitehouse.gov/omb/fedreg/print/directive_15.html> (last accessed July 15, 2003).

[2] Henry J. Kaiser Family Foundation, "Key Facts: Race, Ethnicity & Medical Care, June 2003 Update," p. 8. Specific rates include 7.4 percent for Asians, 7.9 percent for non-Latino whites, 12.9 percent for Latinos, 14.6 percent for non-Latino African Americans, and 17.2 percent for American Indian/Alaska Natives. Ibid.

[3] Jon Perez, testimony before the U.S. Commission on Civil Rights, briefing, Albuquerque, NM, Oct. 17, 2003, transcript, p. 14 (hereafter cited as Briefing Transcript).

[4] Marjane Ambler, "Reclaiming Native Health," *Tribal College Journal of American Indian Higher Education*, vol. 15, Winter 2003, p. 8.

[5] Since 1973 mortality rates have been reduced for the following: tuberculosis (82 percent), maternal deaths (78 percent), infant deaths (66 percent), accidents (57 percent), injury and poisoning (53 percent), and pneumonia and influenza (50 percent). Indian Health Service, *Trends in Indian Health 1998–99*, <http://www.ihs.gov/publicinfo/publications/trends98/part2.pdf> (last accessed Aug. 21, 2003) (hereafter cited as IHS, *Trends in Indian Health 1998–99*). *See also* Perez Testimony, Briefing Transcript, pp. 14, 15.

[6] Perez Testimony, Briefing Transcript, p. 15.

Americans are 770 percent more likely to die from alcoholism, 650 percent more likely to die from tuberculosis, 420 percent more likely to die from diabetes, 280 percent more likely to die from accidents, and 52 percent more likely to die from pneumonia or influenza than the rest of the United States, including white and minority populations.[7] As a result of these increased mortality rates, the life expectancy for Native Americans is 71 years of age, nearly five years less than the rest of the U.S. population.[8] A comparison of earlier life expectancy data illustrates one of the problems facing IHS in eliminating disparities. In 1976, the life expectancy for Native Americans was 65.1 years, compared with 70.8 years for other Americans.[9] Consequently, while life expectancy for Native Americans has improved by six years, the difference in life expectancy relative to other Americans has changed very little. Another problem facing health care providers is the increasing importance of the behavioral component of health status. During the October briefing, Dr. Perez explained that fully seven of the top 10 causes of high morbidity and mortality rates are "directly related to, or significantly affected by individual behavior and lifestyle choices."[10]

The specific health disparities suffered by Native Americans in contrast to other United States populations, including white and minority populations, is discussed below.[11] Information on the health status and outcomes of individual tribes is presented when it illustrates the existence of similar disparities throughout the Native American community. Incidence, prevalence, morbidity, or mortality rates of diseases and health conditions are used to examine and measure those public health issues that disproportionately affect Native Americans.[12]

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[7] *A Bill to Reauthorize the Indian Health Care Improvement Act and H.R. 2440, Indian Health Care Improvement Act Amendments of 2003: Joint Hearing Before the Senate Committee on Indian Affairs and the House Resources Committee, Office of Native American and Insular Affairs*, 108th Cong. (2003) (statement of Dr. Charles W. Grim, director, Indian Health Service). *See also* H.R. 2440, Indian Health Care Improvement Act Amendments of 2003.

[8] U.S. Department of Health and Human Services, Assistant Secretary for Legislation, "Testimony of David Satcher, Assistant Secretary for Health and Surgeon General of the U.S. Public Health Service, U.S. Department of Health and Social [*sic*] Services, Before the House Commerce Committee, Subcommittee on Health and Environment," May 11, 2000, <http://www.hhs.gov/asl/testify/t000511a.html> (last accessed July 15, 2003) (hereafter cited as HHS, "Satcher Testimony"). For 1996–98, the actual life expectancy figures are 70.6 years for Native Americans and 76.5 years for all U.S. races. *See* Indian Health Service, *Facts on Indian Health Disparities*, September 2002.

[9] S. Rep. No. 94-1194, at 15 (1976), *reprinted in* 1976 U.S.C.C.A.N. 2655.

[10] Perez Testimony, Briefing Transcript, p. 19.

[11] The Department of Health and Human Services defines a health disparity as "a population-specific difference in the presence of disease, health outcomes, or access to care." U.S. Department of Health and Human Services, Health Resources and Services Administration, Bureau of Primary Health Care, "Current Needs and Current Issues in Minority Health Research," *UNC 7th Annual Summer Public Health Research Institute on Minority Health*, June 18, 2001, <http://www.cmh.pitt.edu/PPT/H20010614.ppt> (last accessed July 15, 2003) (hereafter cited as HHS, "Current Needs"). Federal, state, and local health agencies measure existing health disparities for specific populations by a variety of "health status indicators." Indicators include incidence, prevalence, morbidity, and mortality rates for a number of illnesses that relate to a particular segment of the population, as well as maternal and infant mortality rates. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, *Healthy People 2000—Statistical Notes: Trends in Racial and Ethnic-Specific Rates for the Health Status Indicators: United States, 1990–98*, January 2002, p. 1 (hereafter cited as CDC, *Trends in Racial and Ethnic-Specific Rates*).

[12] "Incidence is the number of cases of disease having their onset during a prescribed period of time. It is often expressed as a rate (for example, the incidence of measles per 1,000 children 5–15 years of age during a specified year). Incidence is a measure of morbidity or other events that occur within a specified period of time." U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health

Diabetes

Diabetes is one of the most serious health challenges facing Native Americans, resulting in significant morbidity and mortality rates.[13] In fact, American Indians and Alaska Natives have some of the highest rates of diabetes in the world, with more than half of the adult population in some communities having the disease.[14] The National Institute of Diabetes & Digestive & Kidney Diseases (NIDDK) defines diabetes mellitus as a group of diseases characterized by high blood levels of glucose stemming from defective insulin secretion and/or action.[15] Most Native Americans with diabetes have Type 2 diabetes, also known as adult onset diabetes, which is caused by the body's resistance to the action of insulin and impaired insulin secretion. In fact, Native Americans have the highest prevalence of Type 2 diabetes in the world, and rates are increasing at "almost epidemic proportions."[16] Fortunately, Type 2 diabetes can be managed with healthy eating, physical activity, oral medication, and/or injected insulin.[17] Moreover, Dr. Perez testified that one of the most distressing aspects of Type 2 diabetes is that with lifestyle changes it is largely preventable.[18]

Despite the fact that the rates of diabetes in the Native American community are "staggering," the rates do not paint a true picture of how devastating the disease can really be, according to Dr. Dee Ann DeRoin, board member of the Association of American Indian Affairs.[19] Hidden in the fact that the leading cause of mortality in the Native American

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Statistics, "Incidence," *NCHS Definitions*, Aug. 21, 2002, <http://www.cdc.gov/nchs/datawh/nchsdefs/incidence.htm> (last accessed Sept. 20, 2003).

"Prevalence is the number of cases of a disease, infected persons, or persons with some other attribute during a particular interval of time. It is often expressed as a rate (for example, the prevalence of diabetes per 1,000 persons during a year)." U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, "Prevalence," *NCHS Definitions*, Aug. 23, 2002, <http://www.cdc.gov/nchs/datawh/nchsdefs/prevalence.htm> (last accessed Sept. 20, 2003).

The mortality rate is defined as the total or crude death rate from all causes, usually expressed as deaths per 1,000. A disease-specific mortality rate includes those deaths due to one disease and is usually reported per 100,000 persons. The population can be defined by sex, age, or other factors. University of Kansas Medical Center, <http://www.kumc.edu/instruction/medicine/pathology/ed/keywords/kw_mortalit.html> (last accessed Sept. 20, 2003).

The morbidity rate is defined as "[a]n incidence rate used to include all persons in the population under consideration who become clinically ill during the period of time stated. The population may be limited to a specific sex, age group or those with certain other characteristics." University of Kansas Medical Center, <http://www.kumc.edu/instruction/medicine/pathology/ed/keywords/kw_morbidit.html> (last accessed Sept. 20, 2003).

[13] U.S. National Institute of Diabetes & Digestive & Kidney Diseases of the National Institutes of Health, "Diabetes in American Indians and Alaskan Natives," *NIDDK National Diabetes Information Clearinghouse*, <http://www.niddk.nih.gov/health/diabetes/pubs/amindian/amindian.htm> (last accessed July 15, 2003) (hereafter cited as NIDDK, "Diabetes in American Indians"). *See also* Jack Trope, president, and Dee Ann DeRoin, M.D., board member, Association of American Indian Affairs, telephone interview, July 15, 2003 (hereafter cited as Trope and DeRoin interview).

[14] Yvette Roubideaux, MD, MPH, et al., "Measuring the Quality of Diabetes Care for Older American Indians and Alaska Natives, *American Journal of Public Health*, vol. 94, no. 1, 2004, p. 60.

[15] NIDDK, "Diabetes in American Indians." *See also* Trope and DeRoin interview.

[16] Perez Testimony, Briefing Transcript, p. 18.

[17] NIDDK, "Diabetes in American Indians." *See also* Trope and DeRoin interview.

[18] Perez Testimony, Briefing Transcript, p. 18.

[19] Trope and DeRoin interview.

community is heart disease, is the lesser-known fact that the largest percentage of deaths from heart disease is caused by diabetes.[20] Thus, diabetes is both devastating the community in terms of quality of life and "maiming and killing" Native Americans.[21] Though discussed in detail in a later chapter, a preview of funding for diabetes provides yet another measure of the impact of diabetes. According to the IHS FY 2005 Budget Justification, the average economic burden for one person with diabetes is $13,243 per year. Treating diabetes for only those Native Americans who are currently diagnosed with diabetes would amount to $1.46 billion per year, or 40 percent of the total budget for Native American health care.[22]

Another startling fact regarding the prevalence of Type 2 diabetes is that it has recently become a significant threat to Native American children.[23] Its incidence is rising faster among Native American children and young adults than any other ethnic population.[24] IHS has documented a 54 percent increase in the prevalence of diagnosed diabetes among Native American youth 15 to 19 years of age since 1996.[25] Historically, Type 2 diabetes has been restricted to adults, at least partially as a result of declining insulin sensitivity with age.[26] Its presence among children foreshadows the early arrival of more serious complications.[27]

Other national health care authorities have expressed concern about the challenges that diabetes presents for Native Americans of all ages. In 2000, Dr. David Satcher, the Surgeon General of the United States, testified that "the diabetes rate for American Indians and Alaska Natives is more than twice that for whites. The Pima [American Indians] of Arizona have one of the highest rates of diabetes in the world."[28] Furthermore, NIDDK estimates that approximately 15 percent of Native Americans who receive health care from IHS have diabetes.[29] Native Americans are 2.6 times more likely to be diagnosed with diabetes than non-Hispanic whites of a similar age.[30] As troubling as these numbers are, they may understate the number of Native Americans with diabetes. In a screening study conducted in three geographic areas, NIDDK found that 40 to 70 percent of Native American adults between the ages 45 and 74 have diabetes,

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[20] According to the *National Healthcare Disparities Report*, diabetes is the leading cause of blindness, nontraumatic lower extremity amputation, and end stage renal disease; it increases the risk of heart disease, stroke, neuropathy, and complications of pregnancy. *See* U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, *National Healthcare Disparities Report*, December 2003, p. 45 (hereafter cited as HHS, *National Healthcare Disparities Report*).

[21] Trope and DeRoin interview.

[22] U.S. Department of Health and Human Services, *Fiscal Year 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-146.

[23] American Academy of Pediatrics, "Significant Health Disparities Threaten American Indian Children and Youth," press release, Aug. 1, 2002, <http://www.aap.org/advocacy/washing/american_indian.htm> (last accessed Sept. 24, 2003) (hereafter cited as American Academy of Pediatrics, "Significant Health Disparities").

[24] Perez Testimony, Briefing Transcript, p. 18.

[25] American Academy of Pediatrics, "Significant Health Disparities."

[26] Mayo Clinic, "Mayo Clinic Study Finds People Over 40 Need Frequent Exercise to Prevent or Treat Type 2 Diabetes," news release, Aug. 15, 2003, <http://www.mayoclinic.org/news2003-rst/1911.html> (last accessed Aug. 22, 2003).

[27] Perez Testimony, Briefing Transcript, p. 18.

[28] HHS, "Satcher Testimony."

[29] NIDDK, "Diabetes in American Indians."

[30] Ibid. *See also* Perez Testimony, Briefing Transcript, p. 18.

many previously undiagnosed. Data from the Navajo Health and Nutrition Survey showed that 22.9 percent of Navajo adults ages 20 and older had diabetes. At least 14 percent had a history of diabetes, but another 7 percent were found to have undiagnosed diabetes during the survey.[31]

Although measures can be taken to reduce the likelihood of disability and death from diabetes, the disease is still associated with serious health complications and premature death.[32] From 1994 through 1996, the IHS age-adjusted death rates for diabetes mellitus were 350 percent greater than the rates for the rest of the American population.[33] To erase this disparity, Dr. Perez emphasized the prevention of diabetes as a way of eliminating costly treatment options, in addition to reducing the disease burden from the suffering population.[34]

Tuberculosis

Although the tuberculosis rate among Native Americans is declining, it continues to disproportionately affect this population in the number of cases and severity of disease.[35] Tuberculosis is an airborne disease, frequently occurring among people living close together, with poor ventilation, a demographic disproportionately populated by Native Americans.[36] The American Lung Association reported that in 1998, the incidence rate of tuberculosis among Native Americans was 12.6 cases per 100,000 persons, which was more than five times the rate of 2.3 for non-Hispanic whites.[37] By 2002, the tuberculosis incidence rate had dropped to 7 cases per 100,000,[38] approximately twice that of the overall U.S. population, though mortality rates remain six times higher.[39]

Mental Health

Native Americans are at a higher risk for mental health disorders than other racial and ethnic groups in the United States,[40] and are consistently overrepresented among high-need populations for mental health services.[41] The Surgeon General reported that this

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[31] NIDDK, "Diabetes in American Indians."

[32] American Academy of Pediatrics, "Significant Health Disparities."

[33] IHS, *Trends in Indian Health 1998–99*.

[34] Perez Testimony, Briefing Transcript, p. 19.

[35] Jay C. Butler et al., "Emerging Infectious Diseases Among Indigenous Peoples," *Emerging Infectious Diseases*, vol. 7, no. 3 supplement, June 2001, p. 554 (hereafter cited as Butler, "Emerging Infectious Diseases").

[36] Center on Child Abuse and Neglect, "Native Americans and HIV/AIDS," March 2000, p. 3, <http://w3.ouhsc.edu/ccan/AIDS.pdf> (last accessed Feb. 9, 2004).

[37] American Lung Association, "American Indians/Alaskan Natives and Lung Disease," fact sheet, September 2000, <http://www.lungusa.org/diseases/nativelung_factsheet.html> (last accessed Sept. 20, 2003).

[38] Centers for Disease Control and Prevention, National Center for HIV, STD, and TB Prevention, "Reported Tuberculosis in the United States, 2002," Executive Summary, p. 2, <http://www.cdc.gov/nchstp/tb/surv/surv2002/default.htm> (last accessed Feb. 9, 2004).

[39] Butler, "Emerging Infectious Diseases," p. 554.

[40] *See* S. Nelson et al., "An Overview of Mental Health Services for American Indians and Alaska Natives in the 1990s," *Hospital and Community Psychiatry*, vol. 43, 1992, pp. 257–61. *See also* USCCR, *The Health Care Challenge*, p. 46.

[41] High-need populations include the following: people who are homeless, people who are incarcerated, people exposed to trauma, and people with drug and alcohol problems. *See* U.S. Department of Health and Human

overrepresentation might be attributed to the high rates of homelessness, incarceration, alcohol and drug abuse, and stress and trauma in Native American populations.[42] The Surgeon General's report further indicated that the U.S. mental health system is not well-equipped to meet these needs; more specifically, IHS is mostly limited to basic psychiatric emergency care, due to budget constraints and personnel problems.[43] According to Dr. Jon Perez, IHS does not provide ongoing, quality psychiatric care.[44] Instead, the approach adopted by IHS is one of responding to immediate mental health crises and stabilizing patients until their next episode.[45]

The most significant mental health concerns today are the high prevalence of substance abuse, depression, anxiety, violence, and suicide.[46] Substance abuse, most notably alcoholism, has been the most visible health disorder crisis.[47] Depression is also emerging as a dominant concern.[48] These two illnesses are commonly attributed to isolation on distant reservations, pervasive poverty, hopelessness, and intergenerational trauma, including the historic attempts by the federal government to forcibly assimilate tribes.[49]

Alcohol abuse is widespread in Native American communities. Native Americans use and abuse alcohol and other drugs at younger ages, and at higher rates, than all other ethnic groups.[50] Consequently, their age-adjusted alcohol-related mortality rate is 5.3 times greater than

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Services, Office of the Surgeon General, Substance Abuse and Mental Health Services Administration, "Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General," fact sheet, <http://www.surgeongeneral.gov/library/mentalhealth/cre/fact4.asp> (last accessed July 15, 2003).

[42] Ibid.

[43] Judy Nichols, "Special Report—Part 2, Indian Health Care: Critical Condition," *Arizona Republic*, July 21, 2002 <http://www.azcentral.com/news/specials/indianhealth/0721hospital21.html> (last accessed Sept. 24, 2003).

[44] Jon Perez, director of behavioral health, Indian Health Service, interview in Rockville, MD, July 21, 2003 (hereafter cited as Perez interview).

[45] Ibid.

[46] *See* U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, "Cultural Competence Standards in Managed Care Mental Health Services: Four Underserved/Underrepresented Racial/Ethnic Groups," Introduction, <http://www.mentalhealth.org/publications/allpubs/SMA00-3457/intro.asp> (last accessed Sept. 15, 2003).

[47] *See, e.g.*, Kay Culbertson, executive director, Denver Indian Health and Family Services, telephone interview, Sept. 3, 2003; Emery Johnson, interview in Silver Spring, MD, Aug. 8, 2003; Ralph Forquera, executive director, Seattle Indian Health Board, telephone interview, Aug. 27, 2003; Perez interview.

[48] Perez interview.

[49] Perez interview. *See also* S. Rep. No. 94-1194, at 69 (1976), *reprinted in* 1976 U.S.C.C.A.N. 2707.

> Alcoholism in Indians has many underlying causes. It is a means of coping with feelings of anger, frustration or boredom, all of which are related to the comparably low position in which many Indians find themselves today. Inferiority feelings about their lack of education, meaningful employment, status and economic autonomy too often are expressed in excessive drinking.

See also Kevin Gover, Assistant Secretary for Indian Affairs, Department of the Interior (speech at Ceremony Acknowledging the 175th Anniversary of the Establishment of the Bureau of Indian Affairs, Washington, DC, Sept. 8, 2000). "[The] trauma of shame, fear, and anger has passed from one generation to the next, and manifests itself in the rampant alcoholism, drug abuse, and domestic violence that plague Indian Country."

[50] U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Treatment, *Cultural Issues in Substance Abuse Treatment*, 1999.

that of the general population.[51] The Department of Health and Human Services, Substance Abuse and Mental Health Services Administration's *National Household Survey on Drug Abuse* reported the following for 1997:

> 19.8 percent of Native Americans ages 12 and older reported using illegal drugs that year, compared with 11.9 percent for the total U.S. population. Native Americans had the highest prevalence rates of marijuana and cocaine use, in addition to the need for drug abuse treatment.[52]

As identified earlier, depression is the most serious emerging mental health disorder in the Native American population. One of the more troubling indicators of the toll it takes on Native Americans is reflected in suicide rates. From 1985 to 1996, Native American children committed suicide at two and one-half times the rate of white children. During this period, 449 Native American children committed suicide.[53]

The suicide rate for Native Americans continues to escalate and is 190 percent of the rate of the general population. According to the IHS FY 2005 Budget Justification, the highest suicide rate for the general population is found among individuals 74 and older. Among Native Americans, the highest suicide rate is found in the 15-year-old to 34-year-old age range.[54] In fact, suicide is the second leading cause of death for Native Americans 15 to 24 years old and the third leading cause of death for Native American children 5 to 14 years old.[55] Recent data from the American Academy of Pediatrics indicate that in 2002 the youth suicide rate for Native Americans was twice as great among 14- to 24-year-olds, and three times as great among 5- to 10-year-olds, as it was in the general population.[56]

Despite a significant demand for mental health services, there are approximately 101 mental health professionals available per 100,000 Native Americans, compared with 173 mental health personnel per 100,000 whites.[57] With a greater need for mental health specialists, but fewer available for treatment, Native Americans frequently go without the necessary care for substance abuse, depression, anxiety, suicide ideations, and other mental health conditions.

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[51] Ibid.

[52] U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, National Clearinghouse for Alcohol & Drug Information, "Drug Use Among Native Americans Is Higher than Other Racial/Ethnic Groups," *The NCADI Reporter*, Oct. 29, 1998, <http://www.health.org/newsroom/rep/95.aspx> (last accessed July 15, 2003). *See also* CDC, *Trends in Racial and Ethnic-Specific Rates*, p. 11 (between 1990 and 1998, the lung cancer death rate for American Indian and Alaska Natives increased 28 percent).

[53] Eric B. Broderick, *Quantifying the Unmet Need in IHS/Tribal EMS: A project funded by the Office of Program Planning and Evaluation, Office of Public Health, IHS Headquarters, 1999–2001*, pp. 9–10 (hereafter cited as Broderick, *Quantifying the Unmet Need in IHS/Tribal EMS).*

[54] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-60.

[55] IHS, *Trends in Indian Health 1998–99*, p. 66.

[56] American Academy of Pediatrics, "Significant Health Disparities."

[57] U.S. Department of Health and Human Services, Office of the Surgeon General, Substance Abuse and Mental Health Services Administration, "Culture, Race, and Ethnicity—A Supplement to Mental Health: A Report of the Surgeon General," fact sheet, <http://www.surgeongeneral.gov/library/mentalhealth/cre/fact4.asp> (last accessed July 15, 2003).

Unintentional Injuries

Public health authorities consider death and disabilities from unintentional injuries as safety issues affecting all Americans.[58] During the October briefing, Dr. Jon Perez identified unintentional injuries as an issue of particular concern for Native Americans.[59] In fact, unintentional injuries are the leading cause of death for Native Americans under the age of 44 and the third leading cause of death overall.[60] The age-adjusted injury death rate for Native Americans is approximately 250 percent higher than that for the total U.S. population.[61] Moreover, Native Americans suffer injuries at rates 1.5 to 5 times the rates for other Americans.[62] In real terms, this translates to more than 1,300 deaths and more than 10,000 hospitalizations each year for more than 50,000 days of medical care.[63] Outpatient clinics treat an additional 330,000 for injuries.[64] The financial cost of treating these injuries is correspondingly high. Each year IHS spends more than $150 million to treat those suffering from unintentional injuries.[65] Injuries result in 46 percent of all Years of Potential Life Lost (YPLL) for Native Americans.[66] This is five times greater than the YPLL due to the next highest cause, heart disease (8 percent).[67]

Older statistics further subdivide the unintentional injuries category, without obscuring the disparities. From 1985 to 1996 five causes of injury stand out as significant:

- 1,484 Native American children died in motor vehicle crashes, twice the rate for white children. Death rates for the Billings, Navajo, and Aberdeen IHS Areas[68] were more than three times greater than national rates.

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[58] Association of Schools of Public Health, "The Population Approach to Public Health," Apr. 7, 2003, <http://www.asph.org/print.cfm?page=724> (last accessed Sept. 20, 2003).

[59] Perez Testimony, Briefing Transcript, p. 17.

[60] Indian Health Service, "Injuries," *IHS Health and Heritage Brochure—Health Disparities*, <http://www. info.ihs.gov> (last accessed Sept. 26, 2003) (hereafter cited as IHS, "Injuries," *IHS Health and Heritage Brochure*). The causes of death include unintentional motor vehicle crashes, unintentional pedestrian events, firearm use, unintentional drowning, and unintentional fire. *See* Centers for Disease Control and Prevention, *Morbidity and Mortality Weekly Report*, vol. 52, no. 30, Aug. 1, 2003, p. 698.

[61] U.S. Department of Health and Human Services, *Healthy People 2010*, vol. 2, ch. 15, November 2000 (hereafter cited as HHS, *Healthy People 2010*).

[62] IHS, "Injuries," *IHS Health and Heritage Brochure*.

[63] HHS, *Healthy People 2010*.

[64] Ibid.

[65] IHS, "Injuries," *IHS Health and Heritage Brochure*.

[66] HHS, *Healthy People 2010,* ch. 15. Years of Potential Life Lost is a measure of premature mortality. It is calculated using the numbers of deaths in each age group and the difference between the midpoint of the age group and the average life expectancy. *See* U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center for Health Statistics, "Years of Potential Life Lost," *NCHS Definitions*, <http://www.cdc.gov/nchs/datawh/nchsdefs/yearsofpotentiallifelost.htm> (last accessed Dec. 19, 2003).

[67] U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, "Healthy People 2010," Chapter 15 Injury and Violence Prevention, <http://www.healthypeople.gov/document/html/volume2/ 15injury. htm#_Toc490549385> (last accessed Nov. 20, 2003).

[68] The Indian Health Service is organized into 12 regional administrative units called "area offices." Each area office provides administrative support, to include distributing funds, monitoring programs, evaluating activities, and providing technical support to the hospitals, clinics, and other facilities. *See* Indian Health Service, "Indian Health

- 367 Native American children died in pedestrian-related motor vehicle crashes, three times the rate for white children. Death rates for the Albuquerque, Navajo, and Tucson Areas were more than five times greater than national rates.
- 276 Native American children died from drowning, twice the rate for white children. Death rates for the Billings, Navajo, and Aberdeen Areas were more than three times greater than national rates. Death rates for the Alaska Area were more than six times greater than the national rate.
- 224 Native American children died from fire-related injuries, three times the rate for white children. Death rates for the Aberdeen, Alaska, and Bemidji Areas were five times greater than national rates. [69]

MAJOR CARDIOVASCULAR DISEASES

In the past, heart disease and strokes were rare among Native Americans, but recently heart disease has become the number one cause of death; stroke is now the fifth leading cause of death, and the rates are increasing.[70] This dramatic increase appears as the general population has experienced a 50 percent decrease in heart disease; thus, Native Americans now have cardiovascular disease rates twice that of the general population.[71] These soaring rates can be traced to the high rates of diabetes, high blood pressure, and the presence of other risk factors, including poor eating habits and sedentary lifestyles.[72] At least part of the increase may be attributed to an increase in life expectancy. "In 1950, life expectancy for American Indians was 30 years less than for whites. They didn't live long enough to be at risk."[73]

The incidence rates for strokes show similar potential for future problems. Though the death rate for strokes remains lower for Native Americans than the national death rate (39.7 and 61.8, respectively), at lower age brackets the risk is as much as two times higher for Native Americans.[74] As the Native American population continues to live longer the incidence rates for stroke will undoubtedly rise.

The Centers for Disease Control and Prevention (CDC) conducted a national telephone survey to determine the extent that risk factors for heart disease and stroke (i.e., high blood

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Service Introduction," <http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/IHSintro.asp> (last accessed July 15, 2003).

[69] Broderick, *Quantifying the Unmet Need in IHS/Tribal EMS*, pp. 9–10.

[70] Indian Health Service, "Heart Disease & Strokes," *IHS Health and Heritage Brochure—Health Disparities*, <http://www.info.ihs.gov> (last accessed Sept. 26, 2003). This jump in heart disease and stroke is attributed to the gradual improvement of health care for Native Americans. According to Dr. Grim, "the health of Indian Country has changed from one of disease and illness to one of primarily chronic conditions influenced strongly by behavioral and lifestyle issues. *See* Dr. Charles W. Grim, "Eliminating Disparities Is More Than an Access Issue" (remarks before the Association of American Indian Physicians, Santa Fe, NM, Aug. 4, 2003) <http://www.ihs.gov/PublicInfo/PublicAffairs/Director/2003_Statements/FINAL-AAIP_August_2003.pdf> (last accessed Dec. 19, 2003).

[71] Ibid.

[72] Trope and DeRoin interview.

[73] Lois Baker, "Native Americans: Cancer a Growing Health Concern," *SUNY Buffalo Reporter*, Jan. 30, 1997, <http://www.buffalo.edu/reporter/vol28/vol28n18/n1.html> (last accessed Feb. 10, 2004).

[74] For ages 35–44 the relative risk is 2 times greater; ages 45–54 1.3 times greater; and for ages 55–64 it is 1.5 times greater. *See* American Heart Association, *Bio-statistical Fact Sheet*, 2002, p. 2.

pressure, current cigarette smoking, high cholesterol, obesity, and diabetes) were present in the Native American population. According to the survey, 63.7 percent of Native American men and 61.4 percent of Native American women reported having one or more of the surveyed risk factors. The following specific risk factors were reported in significantly high percentages:

- 21 percent of men and 23 percent of women said they had been told by a health professional that they had high blood pressure.
- 32.8 percent of men and 28.8 percent of women reported that they were current smokers.[75]
- Almost 16 percent of respondents had been told by a health care professional that they had high cholesterol and more than 7 percent were told that they had diabetes.
- Almost a fourth of the male respondents (23.6 percent) and nearly one-fifth of the females (19.1 percent) were obese (21.5 percent of all Native Americans).[76]

The CDC also observed that having more than one risk factor for heart disease and stroke was more common among older Native American men and women and several other categories where Native Americans are disproportionately represented, including the unemployed, those with less education, and those reporting their health status as fair or poor.[77] Unless something is changed immediately, cardiovascular disease rates will increase significantly for the aging Native American population.[78]

Pneumonia and Influenza

From 1994 through 1996, the Indian Health Service estimated that the age-adjusted death rate from pneumonia and influenza for Native Americans was 71 percent greater than the rate for the entire U.S. population.[79] In 1998, Native American patients hospitalized for pneumonia

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[75] Native Americans have the highest rates of smoking in adults among all ethnic groups. *See* U.S. Department of Health and Human Services, "Healthy People 2010: Understanding and Improving Health," November 2000, p. 31, <http://www.healthypeople.gov/Document/tableofcontents.htm#under> (last accessed Feb. 9, 2004).

[76] U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Office of Communication, "Facts About Heart Disease and Stroke Among American Indians and Alaska Natives," *Media Relations*, June 2, 2000, <http://www.cdc.gov/od/oc/media/pressrel/r2k0602.htm> (last accessed July 15, 2003) (hereafter cited as CDC, "Facts About Heart Disease and Stroke"). *See also* Georgetown University Center for Child and Human Development, University Center for Excellence in Developmental Disabilities, National Center for Cultural Competence, "Rationale for Cultural Competence in Primary Health Care," *Policy Brief 1*, <http://www.georgetown.edu/research/gucdc/nccc/nccc6.html> (last accessed July 15, 2003) (hereafter cited as Georgetown University, "Rationale for Cultural Competence") (only 50 percent of Native Americans, 44 percent of Asian Americans, and 38 percent of Mexican Americans have had their cholesterol checked within the past two years).

[77] CDC, "Facts About Heart Disease and Stroke."

[78] Dr. Charles W. Grim, "Eliminating Disparities Is More Than an Access Issue" (remarks before the Association of American Indian Physicians, Aug. 4, 2003), <http://www.ihs.gov/PublicInfo/PublicAffairs/Director/2003_Statements/FINAL-AAIP_August_2003.pdf> (last accessed Dec. 19, 2003).

[79] IHS, *Trends in Indian Health 1998–99*. This rate for influenza may be significant since influenza can be particularly severe among diabetic patients. U.S. Department of Health and Human Service, Agency for Healthcare Research and Quality, "National Healthcare Disparities Report," Key Finding 4 - Management of Chronic Diseases Presents Unique Challenges, <http://www.ahcpr.gov/qual/nhdr03/nhdrsum03.htm> (last accessed Dec. 31, 2003).

accounted for the greatest number of hospital discharges for elderly Medicare beneficiaries (49.3 per 1,000 discharges) in the entire U.S. population.[80]

Cancer

Cancer among Native Americans is a growing concern.[81] While statistics indicate lower cancer incidence and mortality rates for Native Americans than for whites, African Americans, Asians, and other races, it has become the leading cause of death for Alaska Native women and is the second leading cause of death among Native American women.[82] An additional concern is the relative comparison of incidence and mortality rates. Although cancer incidence rates are significantly lower for Native Americans (incidence rates for Native Americans are half the rates for whites and less than all other races), cancer death rates are considerably closer (death rates for Native Americans are 70 percent of the rates for whites and greater than the rates for Hispanics/Latinos and Asian/Pacific Islanders). Therefore, the ratio of cancer deaths to new cancer cases is higher for Native Americans than the ratios for all other races.[83] The startling conclusion is that Native Americans have the poorest cancer survival rates among any racial group in the United States.[84]

Furthermore, among health care professionals there is concern that lower mortality rates obscure important regional and cancer-specific differences in mortality, knowledge of which could assist local cancer prevention and treatment strategies.[85] Specifically, higher rates of

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[80] Paul W. Eggers, Ph.D., and Linda G. Greenberg, Ph.D., "Racial and Ethnic Differences in Hospitalization Rates Among Aged Medicare Beneficiaries, 1998," *Health Care Financing Review*, Summer 2000, <http://www.cms.hhs.gov/review/00summer/eggers.pdf> (last accessed July 15, 2003). In comparison, the number of hospital discharges per 1,000 for other racial/ethnic groups, due to pneumonia, included: whites, 22.1; blacks, 22.4; Hispanics, 25.3; and Asians, 17.1.

[81] Native American Cancer Research Corporation, "Native Americans and Cancer," <http://members.aol.com/natamcan/nativeca.htm> (last accessed Dec. 31, 2003).

[82] Centers for Disease Control, "Cancer Mortality Among American Indians and Alaska Natives—United States, 1994–1998," *Morbidity and Mortality Weekly Report*, Aug. 1, 2003, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5230a4.htm> (last accessed Sept. 23, 2003); Native American Cancer Research Corporation, "Native Americans and Cancer," <http://members.aol.com/natamcan/nativeca.htm> (last accessed Dec. 31, 2003). The cancer mortality rate for Native Americans was lower during 1989 through 1993, as compared with the rate for the overall U.S. population. Similarly, for the period 1996 through 2000, Native Americans also experienced one of the lowest mortality rates from invasive cancers (138 deaths per 100,000 persons), compared with other racial and ethnic groups: blacks (257.1), whites (199.1), Hispanics (137.9), and Asian/Pacific Islanders (124.5). Centers for Disease Control, "Cancer Mortality Among American Indians and Alaska Natives—United States, 1994–1998," *Morbidity and Mortality Weekly Report*, Aug. 1, 2003, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5230a4.htm> (last accessed Sept. 23, 2003).

[83] National Cancer Institute, "Cancer Health Disparities," Apr. 23, 2003, <http://www.cancer.gov/newscenter/healthdisparities> (last accessed Feb. 10, 2004).

[84] Native American Cancer Initiative, Inc., "Native American Cancer Research," Chapter 1: Introduction and Background, <http://members.aol.com/natamcan2/cha01.htm> (last accessed Dec. 31, 2003).

[85] American Public Health Association, "Abstract #55992: Regional Patterns of Cancer Mortality in American Indians and Alaska Natives in the U.S., 1994–1998," <http://apha.confex.com/apha/131am/techprogram/paper_55992.htm> (last accessed Sept. 23, 2003) (hereafter cited as American Public Health Association, "Regional Patterns of Cancer Mortality") (David King Espey, M.D., an IHS cancer epidemiologist in Albuquerque, New Mexico, presented his study on regional cancer mortality rates in American Indians and Alaska Natives, before the annual meeting of the American Public Health Association in November 2003).

cancer mortality appeared in Alaska and the Northern Plains region of the United States from 1994 through 1998, with 217.9 and 238.6 deaths per 100,000, respectively.[86] The overall cancer mortality rate for the rest of the United States for this period was 164.2 deaths per 100,000.[87] These Native American cancer mortality rates in Alaska and the Northern Plains region are attributed to colorectal, gallbladder, kidney, liver, lung, and stomach cancers.[88] Similarly, cervical cancer mortality rates were higher among Native Americans than among all racial and ethnic populations (3.7 and 2.6, respectively), especially in the East and Northern Plains regions of the United States.[89]

Though limited data are available, there is insufficient research on cancer among Native Americans.[90] Even with limited data, experts have suggested that Native American cancer patients experience the disease differently from other non-Native populations.[91] Some of the factors contributing to this include genetic risk factors; late detection of cancer; poor compliance with recommended treatment; presence of concomitant disease; and lack of timely access to diagnostic and/or treatment methods.[92] Accordingly, additional research must be conducted to more fully explore cancer disparities among Native Americans.

Infant Mortality and Maternal Health Rates

Infant mortality and maternal health rates are also considered to be indicators of health status for a particular community.[93] Historically, Native Americans have suffered inordinately high infant mortality rates.[94] Despite recent improvement, disparity persists. Native American infants continue to die at a rate 150 percent greater than the rate for white infants.[95] Moreover, Georgetown University's Center for Child and Human Development, National Center for

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[86] American Public Health Association, "Regional Patterns of Cancer Mortality." *See also* Associated Press State & Local Wire, "CDC: Indians in Upper Midwest Have Higher Rates of Cancer Deaths," Aug. 1, 2003, BC Cycle (the Northern Plains region includes Indiana, Iowa, Michigan, Minnesota, Montana, Nebraska, North and South Dakota, and Wyoming).

[87] American Public Health Association, "Regional Patterns of Cancer Mortality."

[88] Ibid. *See also* HHS, *National Healthcare Disparities Report*, p. 39.

[89] Centers for Disease Control, "Cancer Mortality Among American Indians and Alaska Natives—United States, 1994–1998," *Morbidity and Mortality Weekly Report*, Aug. 1, 2003, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5230a4.htm> (last accessed Sept. 23, 2003). *See also* HHS, *National Healthcare Disparities Report*, p. 39 (the East consists of Alabama, Connecticut, Florida, Kansas, Louisiana, Maine, Massachusetts, Mississippi, New York, North Carolina, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Tennessee, and Texas).

[90] Ibid.

[91] Ibid.

[92] Ibid.

[93] HHS, "Current Needs."

[94] CDC, *Trends in Racial and Ethnic-Specific Rates* (between 1990 and 1998 the infant mortality rate for infants of American Indian and Alaska Native women declined by 29 percent).

[95] HHS, *National Healthcare Disparities Report*, p. 58. *See also* Henry J. Kaiser Family Foundation, *Key Facts: Race, Ethnicity & Medical Care, June 2003 Update*, p. 9, listing infant mortality rates by age, ethnicity, and education level of mother.

Cultural Competence, reported that, for Native Americans, the incidence of sudden infant death syndrome (SIDS) is more than three to four times the rate for white infants.[96]

Not surprisingly, maternal health factors also indicate lower health status. Pregnant Native American women are consistently the lowest percentage of women receiving early prenatal care when compared with women of other races and ethnicities. For example, the percentage of Native American women receiving early prenatal care was 69 percent in 2000, compared with 85 percent of white non-Hispanic women.[97]

Recent Progress in Resolving Disparities

The health status of Native Americans confirms the reality that Native Americans have a shorter life expectancy and higher rates of disease than the general population. Nevertheless, their health status has improved as mentioned above and illustrated in the table below:

[96] Georgetown University, "Rationale for Cultural Competence."

[97] HHS, *National Healthcare Disparities Report*, p. 57. These numbers are up slightly from 1995, when the percentage of Native American women receiving early prenatal care was 66.7 percent, compared with 83.6 percent of white non-Hispanic women. *See* Food Research and Action Center, "WIC in Native American Communities: Building a Healthier America," *Report Summary*, 2000, <http://www.frac.org/html/publications/wic01summary.pdf> (last accessed July 15, 2003).

Table 1: Improvements in the Health Status of Native Americans, 1972–1996

Diseases/health conditions	Period	Age-adjusted death rate	Period	Age-adjusted death rate
Injury and poisoning	1972–74	241.7	1994–96	129.7
Accidents	1972–74	188.0	1994–96	92.6
Homicides	1972–74	24.3	1994–96	15.3
Alcoholism*	1972–74	59.0	1994–96	48.7
Chronic liver disease	1972–74	58.3	1994–96	37.2
Pneumonia	1972–74	40.8	1994–96	22.0
Tuberculosis	1972–74	10.5	1994–96	1.9
Gastrointestinal disease	1972–74	6.2	1994–96	1.7
Health indicators		**Years**		**Years**
Life expectancy	1972–74	63.5	1994–96	71.1
Years of potential life lost	1972–74	188.3	1994–96	91.5

* Alcoholism has been increasing since 1985–87
Source: Indian Health Service, *Trends in Indian Health 1998–99*, <http://www.ihs.gov/PublicInfo/Publications/trends98/trends98.asp> (last accessed Feb. 10, 2004).

Most of these improvements may be attributed to increasing access to health care and public health efforts to reduce the effects of infectious diseases. In recent years, the rate of improvement has diminished considerably as disease patterns have changed.[98] Consequently, Native Americans' health status is improving little, both relative to other racial/ethnic groups and in real terms. Given this plateau, there is concern that the lower frequency at which Native Americans access care will erode the previous health status improvements. The *National Healthcare Disparities Report* revealed that Native Americans have worse access to routine health care—as measured by outpatient visits per population, percentage of persons with a dental visit, and percentage of persons with prescription medications—than the general population.[99] Another trend that may further erode progress is found in data from IHS: per capita expenditures for Native Americans accessing IHS services is lower than the national average, and IHS users are served by only half the number of nurses and physicians compared with the national average.[100]

Given that the stated goal of the Indian Health Service is to raise the health status of Native Americans, and that goal has, at best, met with limited success, accountability becomes a significant concern. The starting point for any discussion of accountability for Native American health care is defining the source and the scope of the federal government's responsibility to Native Americans.

[98] Indian Health Service, "Indian Health Service: An Agency Profile," p. 2, <http://info.ihs.gov/IHSProfile.pdf> (last accessed Feb. 10, 2004).

[99] HHS, *National Healthcare Disparities Report*, p. 134.

[100] Indian Health Service, "The IHS Strategic Plan: Improving the Health of American Indian and Alaska Native People Through Collaboration and Innovation," p. 5.

Federal Trust Relationship with Native Americans

The disparities in health status and outcomes experienced by Native Americans are an indictment of the federal government's commitment to fulfilling its moral and legal obligation to provide for the health of Native Americans. This federal obligation is the result of Native Americans ceding over 400 million acres of tribal land to the United States pursuant to promises and agreements that included providing health care services, among other benefits. This federal obligation, from the Native American perspective, was stated very simply by Rebecca Ortega, a member of the Pueblo Santa Clara:

> And us mothers and grandmothers, we don't understand why if we in the treaties . . . gave all our land, [and] our land in the United States of America is worth so much right now. [W]e feel like how come if we gave all that up, why isn't our health care, why hasn't it gone up as well.[101]

The federal government has a special relationship with Native Americans, commonly referred to as a "trust" relationship, requiring the government to protect tribal lands, assets, resources, treaty rights, and health care, among other obligations. The legal source of this trust obligation, however, is imprecise as the boundaries and duties of the trust relationship have evolved over the past two centuries.

The Articles of Confederation[102] contained a general power over Indian affairs, but the Constitution enumerates only one power specific to these affairs: the power "[t]o regulate Commerce . . . with the Indian tribes."[103] In fact, the entire course of dealings between the government and Indian tribes, including various treaties, laws, and hundreds of cases, have all been cited as the source of the trust relationship.[104]

Nevertheless, the origin of federal Indian trust responsibility is usually traced to judicial decisions with subsequent statutory enactments. The first case was *Cherokee Nation v. Georgia*,[105] in which the Cherokee Nation in 1832 sought to prevent Georgia from extending its laws into Cherokee territory. Invoking the original jurisdiction of the Supreme Court, the tribe sought to enjoin enforcement of a Georgia statute that gave the state jurisdiction over persons residing on the tribe's land. The Court held that it lacked original jurisdiction because although the Cherokees were a distinct "political society," they were not a "state" as required by Article III of the Constitution.[106] Rather, the Court concluded that Indian nations "may, more correctly,

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[101] Ortega Testimony, Briefing Transcript, p. 363.

[102] "The United States . . . shall also have the sole and exclusive right and power of . . . regulating the trade and managing all affairs with the Indians, not members of any of the States provided that the legislative right of any State within its own limits be not infringed or violated," U.S. ARTICLES OF CONFEDERATION art. IX (1777).

[103] U.S. CONST. art. I, § 8, cl. 3.

[104] Nell Jessup Newton, *Enforcing the Federal-Indian Trust Relationship After Mitchell*, 31 CATH. U. L. REV. 635, 637–38 (1982).

[105] Cherokee Nation v. Georgia, 30 U.S. (5 Pet.) 2 (1831).

[106] U.S. CONST. art. III. Article III of the Constitution provides that "[i]n all cases affecting . . . those in which a state shall be party, the Supreme Court shall have original jurisdiction. In all the other cases . . . the Supreme Court shall have appellate jurisdiction, both as to law and fact."

perhaps, be denominated domestic dependent nations . . . in a state of pupilage."[107] The relationship of states to Indian nations is similar to "that of a ward to his guardian."[108] The guardian-ward relationship was subsequently used as a justification for Congress' power over Indian tribes, individuals, and resources.

The next year the Supreme Court considered the same Georgia statute giving Georgia jurisdiction over persons residing on the tribe's land and recognized the unique self-governing status of Indian tribes. In *Worcester v. Georgia*,[109] the Court invalidated the statute, holding that Indian tribes are guaranteed protection against interference from the states. The Court held that "the Indian nations had always been considered as distinct political communities within which their authority is exclusive, guaranteed by the United States." The Court found that "the settled doctrine of the law of nations is, that a weaker power does not surrender its independence—its right to self-government, by associating with a stronger, and taking its protection."[110]

These two cases, which recognized Indian nations as domestic sovereigns of the United States, established the trust relationship between the federal government and Native Americans. The cases make clear that only the federal government may negotiate treaties with Indian nations. The cases also determine that only the federal government has jurisdiction over the Indian nations and as trustee must ensure that the states do not interfere with Indian tribes' self governance or encroach on their land.

Against this backdrop, Congress continued to enter into treaties and enact laws; the Supreme Court continued to define the relationship between tribes and the government. The Court reiterated the government's obligations to Native Americans in *Seminole Nation v. United States*,[111] in which the Court restated the "distinctive obligation of trust incumbent upon the Government in its dealings with these dependent and sometimes exploited people."[112] The Court held that:

> [I]n carrying out its treaty obligations with the Indian tribes, the Government is something more than a mere contracting party. Under a humane and self imposed policy which has found expression in many acts of Congress and numerous decisions of this Court, it has charged itself with moral obligations of the highest responsibility and trust.[113]

Accordingly, the federal government has accepted many obligations, including education, construction, law enforcement, and medical services. This health care obligation requires the government to provide medical treatment to all Native Americans living in the United States.

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[107] *Cherokee Nation*, 30 U.S. (5 Pet.) at 17. The Court, however, noted that the Cherokee Nation held similar status to foreign nations in congressional interaction.

[108] *Id*.

[109] Worcester v. Georgia, 31 U.S. (6 Pet.) 515, 557 (1832).

[110] *Worcester*, 31 U.S. (6 Pet.) at 560.

[111] Seminole Nation v. United States, 316 U.S. 286 (1942).

[112] *Id*. at 296.

[113] *Id.* at 296–97.

Federal Responsibility for Health Care

As discussed, the federal government promised health care services to Native Americans in exchange for land very early in the life of this country.[114] The motive for providing health care was not solely altruistic. The government was also attempting to gather information on the numbers of Native Americans; to control the Native American population; and to protect white citizens from the spread of infectious diseases.[115] In 1803, the federal government initially assigned the responsibility for Native American health care to the Office of Indian Affairs in the War Department. Health care duties were subsequently transferred to the newly formed Department of the Interior in 1849, where the responsible office was eventually renamed the Bureau of Indian Affairs (BIA).[116] The BIA administered the funding provided by Congress for health care programs for Native Americans.[117]

Starting in the 1920s, concerns developed regarding the administration of government programs by BIA. Specifically, there were complaints that BIA was poorly equipped to combat public health emergencies, such as tuberculosis, trachoma, smallpox, and other contagious and infectious diseases.[118] Because of these concerns, a commission was formed to inspect reservations, schools, and hospital settings. This commission issued the Meriam Report, documenting substandard health conditions resulting from government inefficiency and inadequate funding.[119] To develop an effective system of preventive medicine and public health, the commission recommended adequately funding Native American health care,[120]spurring a short-lived movement to improve health conditions for Native Americans.[121] In 1955, the division responsible for Native American health care was transferred to the Department of

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[114] Over the past 300 years, Native American nations have traded hundreds of millions of acres to the federal government in exchange for benefits to guarantee the survival and integrity of their tribes, including health care. *See* Indian Health Care Improvement Act Reauthorization of 2003, S. 556, 108th Cong. § 2 (2003). *See also* Holly T. Kuschell-Haworth, *Jumping Through Hoops: Traditional Healers and the Indian Health Care Improvement Act*, 2 DEPAUL J. HEALTH CARE L. 843, 844 (1999) (hereafter cited as Kuschell-Haworth, *Traditional Healers and the Indian Health Care Improvement Act*), *citing* American Indian Policy Review Commission Report on Indian Health: Task Force Six, 1976, p. 33.

[115] "Although U.S. Army surgeons treated Native American victims of smallpox near the opening of the 19th-century, government concern for Native American health at this time was manifest more in counting the numbers of people who died from this and other diseases, and estimating how many were left, than in providing institutional remedies." National Library of Medicine, "Early United States Government Interest in Native American Health," <http://www.nlm.nih.gov/exhibition/if_you_knew/if_you_knew_03.html> (last accessed July 15, 2003).

[116] Kuschell-Haworth, *Traditional Healers and the Indian Health Care Improvement Act*, *citing* American Indian Policy Review Commission Report on Indian Health: Task Force Six, 1976, p. 29.

[117] Ibid.

[118] National Library of Medicine, "Reservation and Hospital Health Care Under the Office of Indian Affairs (c.1890–1925)," <http://www.nlm.nih.gov/exhibition/if_you_knew/if_you_knew_06.html> (last accessed July 15, 2003).

[119] National Library of Medicine, "The Meriam Commission and Health Care Reform (1926–1945)," <http://www.nlm.nih.gov/exhibition/if_you_knew/if_you_knew_07.html> (last accessed July 15, 2003).

[120] Lewis Meriam et al., *The Problem of Indian Administration*, Chapter 1: General Summary of Findings and Recommendations (report of a Survey made at the request of Honorable Hubert Work, Secretary of the Interior, Feb. 21, 1928), <http://www.alaskool.org/native_ed/research_reports/IndianAdmin/Chapter1.html#chap1> (last accessed July 15, 2003).

[121] National Library of Medicine, "Transfer to Department of Health, Education, and Welfare (1946–1969)," <http://www.nlm.nih.gov/exhibition/if_you_knew/if_you_knew_08.html> (last accessed July 15, 2003).

Health and Human Services (HHS). Today, the Indian Health Service (IHS), an agency within HHS, is the principal federal health care provider and health care advocate for Native Americans. The stated IHS goal is to raise the health status of Native Americans to the highest possible level. The IHS health care system includes 49 hospitals in 12 states, 180 health centers in 27 states, and eight school health centers and 273 health stations in 18 states, providing services to approximately 1.4 million Native Americans.

Legislation Assigning Federal Responsibility for Health Care

Perhaps the most significant achievement for Native American health care has been the codification of the federal responsibility in the Snyder Act of 1921.[122] Together, the Snyder Act and the Indian Health Care Improvement Act of 1976[123] form the basic legislative authority for today's Indian Health Service. The Snyder Act was the first major legislation authorizing funding for health care services to Native Americans and reflected congressional recognition of the need to provide ongoing federal health care resources; it was, in fact, the first time Congress formulated broad Native American health policy.[124] Congress charged the Bureau of Indian Affairs to "direct, supervise, and expend such moneys as Congress may from time to time appropriate, for the benefit, care, and assistance of the Indians . . . for relief of distress and conservation of health."[125]

Congress subsequently enacted the Indian Health Care Improvement Act (IHCIA), establishing the basic programmatic structure for delivery of health services to Native Americans and authorizing the construction and maintenance of health care and sanitation facilities on reservations.[126] The wording and effect of IHCIA clearly acknowledged the legal and moral responsibility for "providing the highest possible health status to Indians . . . with all the resources necessary to effect that policy."[127]

Like the Snyder Act, IHCIA provided appropriations authority for the delivery of health services to Native American people. In fact, IHCIA provided comprehensive directives to the federal government regarding the delivery of health care services, including specific language that addressed the recruitment and retention of a number of health professionals serving Native American communities; focused on health services for urban Native Americans; and addressed the construction, replacement, and repair of health care facilities. The act had been amended and reauthorized several times, but was only extended through FY 2001. Although it has expired and has not been reauthorized, Congress has nevertheless continued appropriating funds for IHCIA

[122] Snyder Act of 1921, Ch. 115, 42 Stat. 208 (1921) (codified as amended at 25 U.S.C. § 13 (2004)).

[123] Indian Health Care Improvement Act, Pub. L. No. 94-437, 90 Stat. 1402 (codified as amended in scattered sections of 25 U.S.C.).

[124] Betty Pfefferbaum et al., *Providing for the Health Care Needs of Native Americans: Policy, Programs, Procedures, and Practices*, 21 AM. INDIAN L. REV. 211, 215 (1997).

[125] The Snyder Act of 1921, Ch. 115, 42 Stat. 208 (1921) (codified as amended in 25 U.S.C. 13 (2004)).

[126] Indian Health Care Amendments of 1980, Pub. L. No. 96-537, 94 Stat. 3193 (codified as amended in scattered sections of 25 U.S.C.).

[127] *Id.* In reauthorizing IHCIA in 1990, Congress passed three major health bills amending IHCIA and providing the statutory authorization for a comprehensive and community-based mental health program, the authorization for self-governance demonstration projects, and the expansion of the Urban Indian Health Programs.

programs under the authority of the Snyder Act.[128] Efforts to reauthorize IHCIA are ongoing, with current proposals pending in House and Senate committees.[129] The details of these proposals will be discussed in greater detail in Chapter 5 of this report.

Conclusion

As explained in this chapter, and as will be discussed throughout this report, many factors contribute to health care disparities among Native Americans; not least among them is the historical relationship between tribes and the federal government. An examination of the structure and operation of the Native American health care delivery programs also reveals that the location of health care facilities and the administrative framework of the delivery programs affect access to health care services for many Native Americans. The review of quality of services indicates that, while IHS facilities have received adequate ratings in accreditation surveys, IHS faces significant problems with recruiting and retaining qualified health care providers and maintaining aging facilities. In addition, raising the health status of Native Americans to the level of the rest of the nation requires modification of the Indian Health Care Improvement Act. These modifications must reflect the current health status of the Indian population. But, more importantly, they must recognize that health care for Native Americans is more than simply medical treatment; it involves a holistic approach, including considerations of education, housing, and economic opportunity, as well as empowerment through self-determination and self-governance. Moreover, social and cultural barriers, including racial and ethnic bias and discrimination, cause and contribute to Native American health disparities. Chapter 2 explores the social and cultural barriers limiting Native American access to quality health care and, like the chapters following, presents specific recommendations for change.

[128] The IHCIA has been introduced in the last three sessions of Congress. Mostly because Congress has been preoccupied with national security and other issues of immediate importance, IHCIA has not reached the floor of Congress. Currently two separate versions await action in House and Senate committees. The factors affecting reauthorization and the subsequent impact will be discussed in greater detail in a later section. *See* Myra Munson, Sonosky, Chambers, Sachse, Miller & Munson, LLP, interview in Washington, DC, Aug. 11, 2003.

[129] Traci McClellan, legislative director, National Indian Health Board, e-mail to U.S. Commission on Civil Rights, June 24, 2004. The respective House and Senate committees are awaiting administration input prior to final markup. That input is pending a final Office of Management and Budget evaluation of associated costs. Passage in the current session is possible, but unlikely.

Chapter 2: Social and Cultural Barriers Limiting Native American Access to Health Care and Contributing to Health Disparities

The causes of the disparities in the health status of Native Americans are as many and varied as the tribes themselves. Federal strategies to satisfy the needs of such diverse peoples necessarily encounter various challenges. Among those challenges identified by the director of the Indian Health Service (IHS) is intentional and unintentional racial discrimination.[1] Analyzing the effects of that discrimination requires an understanding of the unique cultural and political history of Native Americans.

In *Eliminating Health Disparities: Conversations with American Indians and Alaska Natives,* Michael Bird, a member of the Santo Domingo and San Juan Pueblo tribes and a former president of the American Public Health Association, describes the historical relationship between Native Americans and the federal government. He describes a relationship and history that have witnessed a military war being waged against Indian Country; Native Americans being dispossessed of millions of acres of land; and a nearly successful effort to wipe out native people and their traditions, beliefs, and culture.[2] These experiences have had a profound impact. According to Mr. Bird, "when you dispossess people of their land or labor, their culture, their language, their tradition and their religion you set into force powerful forces that impact in a very negative and adverse way."[3] He explained that this dispossession promotes and creates health disparities for indigenous populations.[4] From his perspective, Native Americans thrived for thousands of years as independent nations prior to a dispossession policy that created the current conditions of despair.[5] Michael Bird believes that this dispossession has led to "significant damage in health, in educational levels, and in social well-being."[6] A good example of this dispossession policy is the Dawes Act of 1887,[7] which effectively replaced group or tribal ownership of land with individual ownership and made available to white homesteaders land not allotted to individual Native Americans.[8] The assimilation policies of this era sometimes made it illegal to speak traditional languages or practice traditional customs, contributing to the decline

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[1] Dr. Charles W. Grim, testimony before the U.S. Commission on Civil Rights, briefing, Albuquerque, NM, Oct. 17, 2003, transcript, p. 60 (hereafter cited as Briefing Transcript).

[2] Michael E. Bird, "Toward Wisdom," in *Eliminating Health Disparities: Conversations with American Indians and Alaska Natives*, ed. Michael E. Bird, William M. Kane, and Marcia Quackenbush (ETR Associates, 2002), pp. 21–22.

[3] Bird testimony, Briefing Transcript, p. 85.

[4] Ibid.

[5] Ibid.

[6] Michael Bird, "Health and Indigenous People: Recommendations for the Next Generation," *American Journal of Pub. Health*, vol. 92, 2002, p. 1391.

[7] Indian General Allotment Act of 1887, ch. 119, 24 Stat. 388 (codified as amended in 25 U.S.C. §§ 331 *et seq*. (2004)).

[8] Brett Lee Shelton, "Legal and Historical Roots of Health Care for American Indians and Alaska Natives in the United States," February 2004, p.7 <http://www.kff.org/minorityhealth/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=31330> (last accessed August 2, 2004).

in health for many Native Americans.[9] This attempted eradication of native people and their culture was rooted in the belief that they were racially, ethnically, and culturally inferior.

Even today, academic studies find that racial bias significantly contributes to differences in health care provided to Native Americans and other people of color.[10] A recent Institute of Medicine report established that "whites are more likely to receive more, and more thorough, diagnostic work and better treatment and care than people of color—even when controlling for income, education, and insurance."[11]

Though the categorization of bias and discrimination in general terms is possible, discrimination in delivery and quality of health care is often subtle and difficult to address.[12] Consequently, identifying all areas in which race influences or contributes to existing health disparities proves difficult. Current research indicates, however, that in addition to their presence as stand-alone contributors, bias and discrimination exercise a pervasive influence on each of the other primary contributors to disparities in the health status and outcomes for Native Americans. These other contributors to health disparities include:

- Limited access to appropriate health services and facilities.
- Poor access to health insurance, including Medicaid, Medicare, and private insurance.
- Insufficient federal funding.
- Quality of care.
- Availability of culturally competent health services.
- Disproportionate poverty and poor education.
- Behavior or lifestyle choices.

These seven contributors are not mutually exclusive; in fact, there is substantial overlap between each of them. They may also be categorized as social and cultural barriers, structural barriers, and financial barriers. During its investigation, the Commission was provided various examples of how these barriers create disparities in health care for Native Americans. Lyle Jack, a member of the tribal council of the Oglala Sioux Tribe, for example, explained that while his tribe has one of the best rehabilitation centers in terms of equipment, the tribe does not have

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[9] Yvette Roubideaux, "Perspectives on American Indian Health," *American Journal of Public Health*, vol. 92, 2002, p. 1402.

[10] U.S. Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality*, September 1999, p. 73 (hereafter cited as USCCR, *The Health Care Challenge*); *see also* National Institutes of Health, Office of the Director, Office of Behavioral and Social Sciences Research, "Strategic Plan for Health Disparities Research, FY 2002–2006," Mar. 28, 2001, <http://www.obssr.od.nih.gov/Activities/HealthDisp.htm> (last accessed July 14, 2003). *See generally* Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (Washington, DC: National Academies Press, 2002) (hereafter cited as IOM, *Unequal Treatment*).

[11] Vernellia Randall, *Racial Discrimination in Health Care in the United States as a Violation of the International Convention on the Elimination of All Forms of Racial Discrimination*, 14 J. LAW. & PUB. POL'Y 45, 57–8 (2002). *See also* IOM, *Unequal Treatment*, pp. 1–5.

[12] IOM, *Unequal Treatment*, p. 630.

sufficient funding to properly staff that facility.[13] This creates structural and financial barriers, both having negative implications for patient care.

The social and cultural barriers contributing to health disparities include health care providers' bias and stereotyping; cultural understanding and language; patients' socioeconomic status, including poverty and educational attainment; and health behaviors and lifestyle choices. The role of these social and cultural barriers in Native American health disparities is discussed in this chapter.

A discussion of the role of structural barriers—such as management or oversight issues relating to the different types of IHS services, geographic location of facilities, wait times at the facilities and for treatment, the age of facilities, turnover rates of care providers, retention and recruiting of qualified providers, misdiagnosis or late diagnosis of diseases, and rationing of health services—is undertaken in Chapter 3. Financial barriers are discussed in Chapter 4.

Social and Cultural Barriers

Generally, Americans benefit from one of the best health care systems in the world, allowing them to live longer and enjoy better health.[14] Unfortunately, the availability and quality of that care varies between whites and people of color, including Native Americans.[15] Among the various causes are bias and discrimination.

Racial and Ethnic Bias and Discrimination

Racial and ethnic disparities in health have a long history in the United States. For Native Americans, these disparities can be traced back to the arrival of the first settlers and the diseases that accompanied them, diseases for which Native Americans had little to no immunity. Many of the current health disparities are rooted, in part, in past segregationist practices resulting in inferior housing, education, and physical environments, as well as fewer economic opportunities for Native American communities and other communities of color. Though Native Americans share many experiences with other people of color, they also have many unique experiences in the United States. A long history of disenfranchisement; extermination of tradition, language, and land rights; broken treaties; sterilization of Native American women; placement of Indian children in Indian boarding schools; and other experiences of oppression have established deep-rooted intergenerational anger and grief, as well as a mistrust of government that persists to this day. Clearly, these feelings are not unfounded.[16]

Confirming this mistreatment, on September 8, 2000, Kevin Gover, the Assistant Secretary for Indian Affairs of the Interior Department and the highest ranking Native American

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[13] Jack Testimony, Briefing Transcript, p. 24.

[14] U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, *National Healthcare Disparities Report*, December 2003, p. 35.

[15] IOM, *Unequal Treatment*, p. 1.

[16] Holly T. Kuschell-Haworth, *Jumping Through Hoops: Traditional Healers and the Indian Health Care Improvement Act*, 2 DEPAUL J. HEALTH CARE L. 843, 855–56 (Summer 1999). *See also* Levane R. Hendrix, "Health and Health Care of American Indian and Alaska Native Elders," <http://www.stanford.edu/group/ethnoger/americanindian.html> (last accessed Feb. 11, 2004).

at that time, apologized to Native Americans for the mistreatment and abuse they experienced at the hands of the federal government. Mr. Gover, speaking on behalf of the Bureau of Indian Affairs (BIA), apologized for the bureau's historical conduct, stating that federal government policies have left a "legacy of misdeeds that haunts us today . . . Poverty, ignorance and disease have been the product of this agency's work."[17]

Conscious discrimination is not as common as the unconscious bias frequently displayed by health care providers serving Native American communities. Studies have discovered that, while unintentional, health care providers make treatment decisions based on their cultural and racial biases and stereotypes.[18] One study concluded that "[t]oo often, a physician's perception of a patient's race and ethnicity, which is not based on any communication with the patient, is being recorded and used by the health-care team to make clinical decisions and medical and social judgments about the patient. This practice perpetuates physician paternalism and racism."[19] This study assessing disparities in pain treatment found that proper patient-provider communication is necessary to assess a patient's pain.[20]

A report discussing racial and ethnic disparities in the diagnosis and treatment of mental illnesses concluded that disparities can be attributed to bias.[21] Citing a 2001 report, *Race, Culture and Ethnicity and Mental Health*, issued by then-Surgeon General David Satcher, the report concluded that disparities in access and treatment leave minority mental health patients without proper treatment.[22] The report explained that one possible reason for racial and ethnic disparities in mental health treatment is that "practitioners and mental health program administrators make unwarranted judgments about people on the basis of race or ethnicity."[23] Relying on these types of assumptions can lead to inappropriate decisions, and action or inaction, by practitioners and program administrators that affect the overall health care of minorities.[24]

The conclusions of the report are not unique. An independent study by Michelle van Ryn and Steven S. Fu, published in the *American Journal of Public Health*, also found that health providers directly contribute to racial disparities in health care and health outcomes.[25] The research found that providers may intentionally or unintentionally reflect and reinforce societal messages regarding the value, competence, and deservingness of treatment of nonwhite patients.[26] Providers communicate lower expectations for patients of color and poor patients,

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[17] D. Bambi Kraus, "Apology Highlights Abuses in Government's Treatment of Indians," *The Progressive Media Project*, <http://www.progressive.org/mpvdbk00.htm> (last accessed Feb. 11, 2004).

[18] Vence L. Bonham, *Race, Ethnicity, and Pain Treatment: Striving to Understand the Causes of the Disparities in Pain Treatment*, 29 J.L. MED. & ETHICS 52, 61 (Spring, 2001).

[19] Ibid.

[20] Ibid.

[21] Lonnie R. Snowden, "Bias in Mental Health Assessment and Intervention: Theory and Evidence," *American Journal of Public Health*, vol. 93, no. 2, February 2003, p. 239.

[22] Ibid., p. 242.

[23] Ibid., p. 239.

[24] Ibid.

[25] Michelle van Ryn, PhD, MPH, and Steven S. Fu, MD, MSCE, "Paved With Good Intentions: Do Public Health and Human Services Providers Contribute to Racial/Ethnic Disparities in Health?" *American Journal of Public Health*, vol. 93, no. 2, February 2003, p. 252.

[26] Ibid., p. 249.

including the expectation of medical resources and assistance; expectations of improvement in their medical condition; and views concerning family and social support necessary to aid in or support recovery.[27] On a more basic level, interpersonal behavior is also influenced by a provider's bias and use of stereotypes. In the Ryn and Fu study, it was reported that care providers use a "less participatory decision-making style" and communicate information in a highly technical manner with little opportunity for patient input and questions when treating nonwhite and low-income patients.[28] Because of their cultural differences, Native Americans tend not to question physician decisions or speak out against any mistreatment, making them more vulnerable to unfair treatment.[29]

Despite claims by IHS officials that racism and bias are not problems within the IHS system,[30] the Commission found evidence that Native Americans experience bias and discrimination in the health care services they receive through the IHS system. One example of bias and discrimination by IHS providers comes from a Native American woman who sought treatment for constant pain after undergoing a hysterectomy. In explaining her medical condition, she informed her provider that she had two children.[31] The doctor told her that she did not believe her because "no Indian woman only has two children" and required her to undergo painful tests to confirm the hysterectomy.[32]

A second example demonstrates that discrimination can target subgroups within the Native American population, as well. The members of the Health Committee of the Cheyenne River Tribe all agreed that the color of their skin factored heavily when receiving health care services at IHS facilities and that such discrimination was a common complaint among tribal members.[33] The wait time at IHS facilities, they contended, varies depending on the color of their skin; "full-blood Indians" wait longer for services than "lighter skinned Indians." One member said she heard providers at dental clinics commenting on the skin of Native American patients and also expressing their reluctance to provide services to them based on their belief that their skin is "dirty."[34] The chair of the Cheyenne River Sioux Health Committee, Raymond Uses the Knife, stated that this type of discrimination comes from non-Native staff members, who make up more than 40 percent of the IHS staff at the facilities serving the Cheyenne River Sioux

[27] Ibid., pp. 249–51.

[28] Ibid., p. 251.

[29] Ann Garwick and Sally Auger, "What Do Providers Need to Know About American Indian Culture? Recommendations from Urban Indian Family Caregivers," *Families, Systems & Health,* vol. 18, 2000, p. 177 (hereafter cited as Garwick and Auger, "What Do Providers Need to Know?").

[30] Dr. Charles W. Grim, "Eliminating Disparities Is More Than an Access Issue" (remarks before the Association of American Indian Physicians, Santa Fe, NM, Aug. 4, 2003), <http://www.ihs.gov/PublicInfo/PublicAffairs/Director/2003_Statements/FINAL-AAIP_August_2003.pdf> (last accessed Dec. 19, 2003).

[31] Joye Lebeau, Cheyenne River Sioux Tribe Health Hearings, Eagle Butte Hearing, Mar. 12, 2002, p. 23.

[32] Ibid.

[33] Frank Uses the Knife and other Health Committee Members of the Cheyenne River Sioux Tribe, telephone interview, Jan. 20, 2004 (hereafter cited as Knife interview).

[34] Ibid.

Tribe.[35] Based on IHS data, as of 2003, 64 percent of the IHS staff was non-Indian and 36 percent Indian.[36]

Not all bias is so obvious; subtle comments or innuendos may also reflect discriminatory attitudes. In Eagle Butte, South Dakota, an IHS facility refused to take in a Lakota elder, found unconscious at home by his wife.[37] A non-Native American provider in charge at IHS, when asked by the ambulance driver where to take the person, allegedly stated, "Whatever you do, don't bring the body to IHS. I don't care if you take it back or throw it on the side of the road, just don't bring it here."[38] This tragedy caused uproar in the Lakota Nation. Whether the statement was insensitive or an example of discrimination against Native Americans, the tribal members of the Lakota Nation perceived this statement as discriminatory. For the tribal members, this blatantly offensive statement was emblematic of the racial discrimination, disrespect, and mistreatment of Native Americans by IHS staff that they had long suspected.[39] This event confirmed the "generations of resentment at perceptions of callous, indifferent treatment from the IHS."[40] These illustrations are just a few examples of many shared by Native Americans of the disrespect, mistreatment, and racial discrimination at IHS facilities.

As corroborated by anecdotal evidence and empirical studies, the Commission has found that racism, racial bias, and the mistreatment of minorities and Native Americans are real—and cause real health disparities.[41] As long as medical decisions are made based on stereotypes or racial bias, Native Americans will have shorter life spans and a reduced quality of life.

Cultural Understanding and Language

For Native Americans, there is a concern that health care providers' cultural insensitivity and the lack of acceptance of traditional healing practices and traditional medicine may create barriers to receiving care.[42] Accordingly, it is important that "culturally competent"[43] health

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[35] Ibid.

[36] U.S. Department of Health and Human Services, Indian Health Service, Response to the Commission's Interrogatory 45, April 2004 (hereafter cited as IHS, Interrogatory Response). *See also* U.S. Department of Health and Human Services, Indian Health Service, *Fiscal Year 2005 Budget Justification, Indian Health Professions*, p. IHS-119.

[37] Kay Humphrey, "Indian Health Service Accused of Neglect in Tribal Elder's Death," *Indian Country Today*, Jan. 25, 2002 (hereafter cited as Humphrey, "IHS Accused of Neglect in Tribal Elder's Death").

[38] Ibid.

[39] Knife interview.

[40] Humphrey, "IHS Accused of Neglect in Tribal Elder's Death."

[41] Saffron Karlsen and James Nazroo, "Relation Between Racial Discrimination, Social Class, and Health Among Ethnic Minority Groups," *American Journal of Public Health*, vol. 92, 2002, p. 630; Stephen B. Thomas, "The Color Line: Race Matters in the Elimination of Health Disparities," *American Journal of Public Health*, vol. 91, 2001, p. 1047; Lonnie R. Snowden, "Bias in Mental Health Assessment and Intervention: Theory and Evidence," *American Journal of Public Health*, vol. 93, 2003, pp. 241–42.

[42] USCCR, *Health Challenges*, p. 44.

[43] Cultural competence is defined as the demonstrated awareness and integration of three population-specific issues: health-related beliefs and cultural values, disease incidence and prevalence, and treatment efficacy. The Henry J. Kaiser Family Foundation, "Compendium of Cultural Competence Initiatives in Health Care," January 2003, p. 6, <http://www.kff.org/content/2003/6067/6067v6.pdf> (last accessed Sept. 17, 2003).

services be available to Native Americans. If health services are not offered to the targeted patient population in a culturally and linguistically appropriate manner, treatment will remain ineffective and any effort to eliminate racial and ethnic health care disparities will fall short.[44]

The importance of culturally competent health services to the overall quality of health care has been generally acknowledged.[45] Moreover, authorities realize the necessity of offering health care that recognizes and complies with the patient's values, beliefs, and traditions, in order to provide acceptable services for specific populations.[46] According to the Department of Health and Human Services:

> Health care providers typically presume they are color blind in their delivery of services. Few providers have thought about the biases they bring to patient encounters or about their own cultural/ethnic backgrounds, health beliefs, and health practices. These biases often result in both the system and its providers attempting to get the patient to conform to the mainstream instead of meeting a patient on her or his own cultural ground. Yet patient attitudes about health, religious views, and concepts of death often influence compliance, affect disease management, and alter health outcomes.[47]

If culturally and linguistically appropriate health services are desirable to Native Americans, based on their unique cultures and the unique relationship with the federal government, distinctive approaches to health care should also be included in the delivery of health services to this population. Many Native Americans continue to employ traditional medicines and practices either as their sole form of health care or as a component of their overall health care.[48] Accordingly, in March 2002, the Association of American Indian Physicians unanimously approved a resolution acknowledging and supporting Native American traditional healing and medicines as part of the spectrum of health care appropriate for Native Americans. As part of this resolution, the association intends to work collaboratively with traditional healers for the benefit of Native patients and community health.[49]

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[44] *See generally* IOM, *Unequal Treatment*.

[45] Ibid.

[46] U.S. Department of Health and Human Services, Public Health Reports, "Culturally Competent Health Care," *Public Health Report 2000*, by Jean Lau Chin, Ed.D., vol. 115, January–February 2000 (hereafter cited as HHS, *Public Health Report 2000*). *See also* Johnson interview. Dr. Emery Johnson, former director of the Indian Health Service, discussed what happens when cultural competency is not considered. Dr. Johnson mentioned a Cornell University study, where a high-tech medical facility was placed in an impoverished rural setting. The study found that the high-tech program resulted in little improvement in health status, which was eventually attributed to a lack of understanding and acceptance in the rural community. *See also Harvard Public Health Now*, "MPH Student Blends Native American and Modern Medicine to Address Health Disparities," May 31, 2002, <http://www.hsph.harvard.edu/now/may31/student.html> (last accessed July 15, 2003); J. Patterson, "Meeting the Needs of Native American Families and Their Children with Chronic Conditions," *Families, Systems & Health*, vol. 15, 1997, pp. 237–41. *See generally* USCCR, *The Health Care Challenge, Vol. I*, pp. 44–45.

[47] HHS, *Public Health Report 2000*.

[48] Jennie Joe, "The Rationing of Healthcare and Health Disparity for the American Indians/Alaska Natives," in Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (National Academies Press, Washington, DC, 2002), p. 537 (hereafter cited as Joe, "The Rationing of Healthcare").

[49] Association of American Indian Physicians, "Resolution," Mar. 13, 2002, <http://www.aaip.com/about/AAIP_trad_med_resol_02.html> (last accessed July 15, 2003).

In a study to identify what urban Indian family caregivers should inform health providers who work with Native American children about Indian culture, the caregivers concluded that providers should be aware of the role and importance of extended family members in a child's overall care, any traditional health beliefs and healing practices, and any cultural communication patterns.[50] Specifically, health facilities should avoid excluding extended family members who might want to visit a child, since they may also assist in serving as primary caregiver to Native American children.[51] In terms of traditional beliefs, some Native American families may resist Western treatment recommendations and prefer to use herbal remedies, healing ceremonies, and traditional healers as a primary or supplemental form of treatment.[52] Furthermore, the study indicated that health providers should be aware of the significance of nonverbal communication for some Native American patients, such as indirect eye contact and silence.[53] These forms of nonverbal communication are often an indication of respect for the "healer," and may prevent some patients from directly asking questions or requesting health care services.[54] Cultural competence, therefore, acknowledges the patient's perspective and adjusts appropriately, inevitably improving the quality and delivery of care. Reaching that level of competence requires insight, extensive training, and a programmatic commitment to cultural sensitivity. Accordingly, as the advocate for Native American health and as the federal health care provider for eligible Native Americans, IHS has the responsibility of ensuring, through its training and programming, that IHS health care services are provided in a culturally competent manner.

Generally, IHS recognizes the importance of culturally competent care. Dr. Charles W. Grim, director of IHS, cited cultural and language barriers as factors that affect health disparities and access to health care.[55] He added that IHS is working to make its programs culturally relevant, and as a result, cultural competence is losing significance as a factor for accessing IHS services.[56] Dr. Richard Olson, acting director of Office of Clinical and Preventive Services, also acknowledged that cultural competence is an aspect of quality of care.[57] IHS defines "culturally competent care" as "a term implying that IHS programs and staff should be aware, sensitive, and accommodating of a wide diversity of Native languages, customs, beliefs, values, and traditions of healing and wellness."[58]

While IHS acknowledges that culture and language can be barriers to care for over 560 federally recognized tribes, many with their unique cultures and languages, IHS claims that, because it employs a high percentage of Native American staff, cultural competency is not a major issue at IHS.[59] According to IHS, it "recognizes the value of traditional beliefs,

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[50] Garwick and Auger, "What Do Providers Need to Know?" p. 177. The study included a small sample of 30 Native American families from three tribes: 27 Ojibwe, two Lakota, and one Dakota in a large Midwestern city. The authors note that the results of this study may not be the same for families of other urban Indian tribes.

[51] Ibid.

[52] Ibid.

[53] Ibid.

[54] Garwick and Auger, "What Do Providers Need to Know?" p. 177.

[55] Grim Testimony, Briefing Transcript, p. 62.

[56] Ibid., pp. 62, 65.

[57] Olson Testimony, Briefing Transcript, p. 128.

[58] IHS, Interrogatory Response 1.

[59] IHS, Interrogatory Responses 47 and 48.

ceremonies, and practices in the maintenance of wellness and the healing of the body, mind and spirit."[60] Therefore, IHS encourages an atmosphere where traditional beliefs are upheld and respected to ensure that they are a vital force within Indian communities and that those traditional beliefs remain an integral component of the healing process.[61] Furthermore, IHS makes traditional medicine, as defined by tribal or village traditional culture, accessible in all its service delivery locations.[62] IHS is also designing and constructing its new clinics and hospitals to include space for spiritual healing practices.[63]

In terms of whether IHS facilities are successfully delivering culturally competent health services, a focus group of Native Americans in Albuquerque, New Mexico, revealed that participants were generally satisfied with IHS providers' awareness of the significance of Native American culture.[64] This finding tends to support Dr. Grim's testimony that cultural and language barriers have become less of an issue for IHS services.[65] However, despite Dr. Grim's statement that IHS provides training for non-IHS providers at contract facilities,[66] the findings from the Albuquerque focus group revealed Native American patients' dissatisfaction with biased behavior and cultural insensitivity toward the importance of traditional medicine by health care providers from the private sector.[67]

Supporting the general findings of the Albuquerque focus group, tribal representatives and leaders with whom the Commission spoke agreed that, generally, cultural competency is not a major concern when accessing IHS direct services.[68] The sense of dissatisfaction with a lack of cultural sensitivity derives primarily from services provided to Native Americans by contract health providers.[69] When asked to provide specific information on the number and the types of administrative and judicial complaints concerning the IHS direct, tribal, and contract health services, IHS merely responded that the Contract Health Services program does not maintain complaint-related data.[70] Because of IHS' failure to provide requested information on any complaints concerning the quality of care provided at IHS direct, tribal, and contract health facilities, it is difficult to assess the degree to which the lack of culturally competent care is affecting the quality of care Native Americans receive.

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[60] Ibid.

[61] Ibid.

[62] Ibid.

[63] Ibid.

[64] Joe, "The Rationing of Healthcare," p. 538.

[65] Grim Testimony, Briefing Transcript, pp. 62, 65.

[66] Ibid., p. 66.

[67] Joe, "The Rationing of Healthcare," p. 538.

> IHS facilities and its leadership in many communities have always allowed patients and their families either time or a place (in a clinical setting) to consult with tribal healers or practitioners. The services provided by most of these tribal healers or practitioners are seen as complementing modern medicine and provide a source of spiritual help for many patients.

Ibid.

[68] *See* Chris Walker, executive director, Cherokee Health Services, interview in Washington, DC, Apr. 23, 2004; Alan Burgess, tribal health administrator, Owyhee Community Health Facility, telephone interview, May 12, 2004.

[69] Ibid.

[70] IHS, Interrogatory Response 38.

Nonetheless, the findings from the Albuquerque focus group and the responses from some tribal representatives suggest that when IHS refers Native American patients to contracted health providers, these providers should be extensively apprised and trained about the cultural and linguistic needs of all patients who seek their health services.[71] Furthermore, though cultural competency among IHS providers seems to be less of a concern, cultural competency training, nonetheless, is an important step toward improving the quality of care provided to Native Americans. While having a large percentage of Native American IHS staff is encouraging, as IHS has recognized, many Native American tribes have their own unique cultures and languages; unless the IHS staff belong to the same tribe and culture as the health care recipients, Native American patients may encounter cultural barriers in accessing IHS services.[72] The IHS recognizes that many non-Native American providers need cultural training concerning the local customs and beliefs.[73] The IHS also recognizes that helping IHS health providers develop cultural competency makes them more effective in providing quality health care services to Native Americans.[74]

Unfortunately, the dissatisfaction found by the focus group indicates that the cultural training IHS provides may be insufficient for addressing cultural barriers for Native Americans. Despite the recognized importance and need for cultural competency training, IHS does not have a specific budget set aside for training its IHS direct or contract health service providers.[75] The IHS reports that some formal and informal training is conducted at the area or local level.[76] However, IHS did not provide specific information as to how managers have sought to incorporate culturally competent care into the delivery of health services at IHS and non-IHS facilities. In addition, IHS did not provide the requested information on the impact or outcome of its efforts to incorporate culturally competent care into the delivery of care on the health status and outcomes for Native Americans. Overall, despite requests for detailed and specific information on IHS training and policy implementation efforts to ensure culturally competent care, IHS was unable to identify monitoring mechanisms, training initiatives, or targeted funding indicative of the commitment needed to develop cultural competency in the delivery of health services at IHS and non-IHS facilities.

In addition to cultural barriers, language barriers present obstacles to communication with providers for those Native Americans who maintain their traditional language. These obstacles necessarily increase the difficulty of receiving care and understanding treatment procedures and provider instructions. Research has found that non-English proficient and limited English proficient patients:

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[71] *See, e.g.,* Anslem Roanhorse, Jr., division director, Navajo Division of Health, telephone interview, Sept. 24, 2003 (For contracted services, Navajo-speaking staff are on call to provide translation services, if needed, on a 24-hour basis. Orientation and training about the Navajo culture is done for contracted providers).

[72] Cherokee Nation, interview in Tulsa, OK. A Native American provider from a different tribe than the patient wore jewelry thought to be insensitive to the patient's culture.

[73] IHS, Interrogatory Responses 47 and 48.

[74] Ibid.

[75] Ibid.

[76] Ibid.

- Receive less information about the therapeutic regimen for their condition and understand fewer of the instructions related to medication.
- Are less likely to keep subsequent appointments and are more likely to make emergency room visits than patients in same-language encounters.
- Are less likely to receive preventive services.[77]

Many studies have also found that patients with limited English proficiency cite the language barrier as an obstacle to receiving care.[78] In addition, language obstacles create problems for patients in understanding provider instructions.

According to the 2000 census, 381,000 Native Americans speak a native North American language, representing an increase from the 281,990 identified in the 1990 census. The most common of the Native American languages is Navajo, with 178,014 speakers.[79] While language assistance needs vary among Native American tribes, for those Native Americans whose primary language is other than English, language assistance is crucial to ensuring that they receive proper health services.

Currently, IHS does not provide formal language assistance to its patients.[80] In many situations, IHS programs may have staff and employees who speak the same language as the patients and provide informal translation.[81] At other times, patients themselves bring family members to act as translators.[82] This informal translation is problematic as it can cause semantic errors and breaches of confidentiality, and may even disturb familial hierarchies and relationships.[83]

The IHS reports that lack of language assistance is not a major problem within its direct facilities, though IHS has identified language barriers as affecting access to care for Native Americans whose primary language is not English.[84] The language assistance needs at contract facilities, however, are unclear. Generally, non-IHS facilities do not have staff capable of acting as translators for Native Americans.[85] Aside from occasional language assistance provided by family members, patients can be expected to encounter communication problems with their providers at non-IHS facilities. Nonetheless, IHS has failed to devote resources and has failed to implement any formal assistance measures to address this barrier.

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[77] The Robert Wood Foundation, "Working Toward Dismantling the Language Barrier in Health Care," <http://www.rwjf.org/news/special/languageBarrier_2.jhtml> (last accessed Mar. 9, 2004).

[78] Barbara Plantiko, *Not-So-Equal Protection: Securing Individuals of Limited English Proficiency with Meaningful Access to Medical Services*, 32 GOLDEN GATE U.L. REV. 239, 241 (Spring 2002).

[79] U.S. Census Bureau, "Facts for Features: American Indians and Alaska Natives," <http://www.census.gov/Press-Release/www/releases/archives/facts_for_features/001492.html> (last accessed Mar. 17, 2004).

[80] IHS, Interrogatory Responses 47 and 48.

[81] Ibid.

[82] Ibid.

[83] Barbara Plantiko, *Not-So-Equal Protection: Securing Individuals of Limited English Proficiency with Meaningful Access to Medical Services*, 32 GOLDEN GATE U.L. REV. 239, 240 (Spring 2002).

[84] IHS, Interrogatory Responses 47 and 48.

[85] Melissa Charlie, Navajo Nation, telephone interview, Apr. 30, 2004.

Socioeconomic Status: Education and Poverty

Lower income and educational levels are associated with poor overall health status and health outcomes.[86] Due in part to past and present discrimination in education and employment, Native Americans and other people of color achieve lower levels of educational attainment and income. Native Americans, however, have the highest poverty rate of any ethnic group.[87] They have a poverty rate of 25.9 percent, while the poverty rate is 22.1 percent for African Americans, 10.8 percent for Asian/Pacific Islanders, and 21.2 percent for Hispanics.[88] In comparison, while the national poverty rate is 11.3 percent, only 7.5 percent of whites live below the poverty level.[89] Native Americans remain at the bottom in almost every measurable economic category and earn only about half of that earned by the average American.[90]

On Indian reservations, poverty levels for Native Americans are significantly worse. Among the Navajo, for example, over 50 percent live below the poverty level and almost 50 percent are unemployed.[91] More than 50 percent of homes rely only on wood burning for heating, 32 percent lack adequate plumbing, and 60 percent lack telephone service.[92] On the Pine Ridge Reservation in South Dakota, the unemployment rate hovers around 80 percent and two out of three residents live below the poverty level.[93]

Throughout Indian Country, poverty has had a devastating effect on the health and well-being of Native Americans. Native Americans are faced with high unemployment rates resulting from lack of economic opportunities on the reservations. Frequently, poverty and the lack of economic opportunities lead to inadequate housing. A new study by the Housing Assistance Council, a national rural housing organization, found that poverty, the lack of economic opportunity, and the shortage of financing for affordable housing have led to deplorable housing

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[86] USCCR, *The Health Care Challenge*, p. 17. *See also Health Disparities: Bridging the Gap: Hearing Before the Subcomm. on Public Health of Senate Comm. on Health, Education, Labor and Pensions*, 106th Cong. (2000) (testimony of Ruth L. Kirchstein, acting director, National Institutes of Health), and E. Pamuk, D. Makuc, K. Heck, C. Reuben, and K. Lochner, *Socioeconomic Status and Health Chartbook. Health, United States, 1998*, p. 25 (Hyattsville, MD: National Center for Health Statistics, 1998) (hereafter cited as Pamuk et al., *Socioeconomic Status and Health Chartbook*).

[87] Housing Assistance Council, *Taking Stock: Rural People, Poverty, and Housing at the Turn of the 21st Century*, p. 96 (hereafter cited as Housing Assistance Council, *Taking Stock*).

[88] *See* U.S. Census Bureau, Public Information Office, "Nation's Household Income Stable in 2000, Poverty Rate Virtually Equals Record Low," *Census Bureau Reports*, Sept. 25, 2001, CB01-158.

[89] Mary Anne Bobinski, *Health Disparities and the Law: Wrongs in Search of a Right*, 29 AM. J.L. & MED. 363, 373 (2003); U.S. Census Bureau, Public Information Office, "Nation's Household Income Stable in 2000, Poverty Rate Virtually Equals Record Low," *Census Bureau Reports*, Sept. 25, 2001, CB01-158.

[90] Peter Carlson, "In the Year of 'Dances with Wolves,' Everybody Wanted to Be on the Senate Indian Affairs Committee. Nearly a Decade Later, It Can Hardly Get a Quorum," *Washington Post*, Feb. 23, 1997, p. W06 (hereafter cited as Carlson, "Everybody Wanted to Be on the Senate Indian Affairs Committee").

[91] Kathy Helms, "Navajo Poverty Cited in Pursuit of Fed Funds," *Gallup Independent*, <http://www.gallup independent.com/031204poverty.html> (last accessed Mar. 17, 2004); Roanhorse Testimony, Briefing Transcript, p. 139.

[92] Roanhorse Testimony, Briefing Transcript, p. 139.

[93] Carlson, "Everybody Wanted to Be on the Senate Indian Affairs Committee."

conditions for Native Americans living on reservations. Substandard housing has been long recognized as contributing to worse health outcomes.[94]

While the specific problems vary from tribe to tribe, in general, Native Americans living on reservations in rural areas live in poor housing conditions. Overcrowding in Native American households is three times the national rate.[95] Overcrowding and substandard housing conditions are linked and often lead to increased incidences of tuberculosis, pneumonia, gastrointestinal disorders, head lice, conjunctivitis, hepatitis, and a variety of other infectious diseases that are easily transmitted in crowded spaces.[96]

Another housing problem is affordability. Native Americans spend over 30 percent of their household income for housing each month.[97] A more serious housing problem is lack of adequate plumbing.[98] While 4 percent of Native Americans nationwide live in housing that lacks adequate plumbing, about 10 percent of Native Americans living on reservations have inadequate plumbing; this figure is 10 times the national level.[99] In addition, while only 0.7 percent of U.S. households lack kitchens, 8.7 percent of Native American households lack kitchens.[100] The Housing Assistance Council attributes Native American housing problems to the lack of financing for decent homes because of legal, socioeconomic, and cultural constraints.[101]

Poverty and substandard housing go hand in hand. One way to improve housing conditions in Indian Country is to reduce the high poverty and unemployment rates and provide more economic opportunities on the reservations. Unfortunately, very few economic opportunities exist on the reservations. Despite the common belief that gambling casinos on reservations have brought increased economic opportunities for Native Americans, studies indicate that only a few tribes have benefited from gaming.[102] Data show that gaming on the reservations has yet to reduce poverty among Native Americans.[103]

Persistent poverty results in substandard housing for Native Americans. Both poverty and substandard housing conditions have led to serious health effects. It is generally recognized that income relates to health status because it increases access to care, enables living in better homes

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[94] Shobha Srinivasan, Liam R. O'Fallon, and Allen Dearry, "Creating Healthy Communities, Healthy Homes, Healthy People: Initiating a Research Agenda on the Built Environment and Public Health," *American Journal of Public Health*, vol. 93, 2003, p. 1447; James Krieger and Donna L. Higgins, "Housing and Health: Time Again for Public Health Action," *American Journal of Public Health*, vol. 92, 2002, p. 758.

[95] Housing Assistance Council, *Taking Stock*, p. 100.

[96] Ibid.

[97] Ibid.

[98] Ibid.

[99] Ibid.

[100] Housing Assistance Council, *Taking Stock*, p. 100.

[101] Ibid.

[102] Ibid.

[103] Native Americans in Philanthropy, "Survey of Grant Giving by American Indian Foundations and Organizations," <http://www.hartford-hwp.com/archives/41/067.html> (last accessed Mar. 17, 2004); Associated Press, "Indians See Little from $8 Billion in Gambling Revenue," Aug. 31, 2000, <http://www.hartford-hwp.com/archives/41/389.html> (last accessed Mar. 17, 2004). *See also* Chapter 4.

and neighborhoods, and increases opportunities to engage in healthy lifestyles.[104] Because Native Americans have the highest poverty and unemployment rates, their health is inevitably compromised.

Generally, Americans living near or below the poverty level suffer from worse health than wealthier Americans and, at age 45, have a life expectancy three to seven years shorter than those with higher incomes.[105] While 27 to 37 percent of men living below the poverty line report being in fair or poor health, only 4 to 5 percent of high-income men report this. The results for women are similar.[106]

One possible explanation for poor health outcomes for those living in poverty is inadequate access to medical care. Men and women living below the poverty line are almost five times more likely to have an unmet need for health care than adults with high family income.[107] Poor women are three times as likely as high-income women to have gone without seeing a doctor in the past year; poor men are twice as likely as high-income men.[108] Conversely, wealthier, more educated people are more likely to have better access to medical care and safer home and work environments.[109] In addition, they have more opportunities to engage in healthy activities and lifestyles, are more aware of health issues, and are better able to pursue healthy behaviors.[110]

A discussion of the role of poverty is incomplete without acknowledging related barriers, such as poor transportation and the absence of child care. When these problems were resolved for Native American women as a part of a breast cancer screening program, no impact on the participation rates was noticed. Women interviewed explained that their lack of participation in the program was not based on poverty-related issues, but instead attributed their reluctance to the perception that once they were diagnosed with cancer there would be no treatment or that treatment would be unavailable to them.[111] These fears cannot be quickly dismissed. Linda Burhansstipanov found in her breast cancer work with Native American women that "the interval from the time of diagnosis . . . to initiation of treatment is three to six months. Unless they have private insurance." Few Native American women, less than a third, have insurance.[112]

Lack of education, considered alone, has historically been a very strong indicator of poor health. Among all racial and ethnic groups, men with less than 12 years of education are 2.5 times more likely to die from a chronic disease than men with more than 12 years of education.[113] The ratio for women is 2.1, and similar rates are passed from generation to

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[104] Pamuk et al., *Socioeconomic Status and Health Chartbook,* p. 29.

[105] Ibid.

[106] Ibid.

[107] Ibid.

[108] Ibid.

[109] Ibid.

[110] Ibid.

[111] Linda Burhansstipanov, "Leaders and Survivors," in *Eliminating Health Disparities: Conversations with American Indians and Alaska Natives,* eds. Michael E. Bird, William M. Kane, and Marcia Quackenbush (ETR Associates, 2002), pp. 38–39.

[112] Ibid., p. 39. *See also* Chapter 4.

[113] Pamuk et al., *Socioeconomic Status and Health Chartbook,* p. 90.

generation.[114] Infant mortality rates almost double for infants whose mothers have less than a high school education.[115]

Adults with less education are also more likely to exhibit risk factors known to contribute to chronic health problems and have more difficulties gaining access to medical care. For example, mothers with more education are 40 percent more likely to have received early prenatal care than mothers with less than 12 years of education.[116] Less educated mothers are almost 10 times as likely to smoke during pregnancy as more educated mothers.[117] Furthermore, heavy alcohol use, which can lead to cirrhosis, increased accident rates, and fetal alcohol syndrome, among other health problems, is 30 percent higher among adults with less than a high school education than it is among college graduates.[118]

Higher levels of education increase exposure to health-related information, equip individuals with the skills necessary to apply health-promoting behavior, and are typically associated with higher incomes.[119] Unfortunately, Native American educational levels are significantly lower than the national average.[120] According to the 2000 census, of the population over the age of 18 who did not have a bachelor's degree, Native Americans had the highest percentage living below the poverty level, at 38.2 percent.[121]

Armed with this knowledge about the role lack of education plays in limiting access to medical information and services, health care providers serving Native American communities should be required to provide information and services in ways understandable and usable to those with limited education and skills. The failure to do so contributes to increasing the incidence of preventable disease and the late-stage diagnosis of conditions such as cancer and diabetes. As a result, more money will be spent on treatment in the long term, mortality rates in the Native American population will stagnate or increase, and the quality of life for many Native Americans will be greatly diminished.

With culturally appropriate and skills-appropriate prevention and intervention programs, diabetes, one of the major health challenges for Native Americans, can be treated and managed, because it is closely related to behavioral issues. Improved programs could prevent more stories

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[114] Ibid.

[115] Ibid.

[116] Ibid.

[117] Ibid.

[118] Ibid.

[119] Ibid., p. 30.

[120] In 2000, 70.9 percent of Native Americans 25 and older had graduated from high school, compared with 80.4 percent for the total population. A total of 83.6 percent of whites had graduated from high school. Furthermore, 11.5 percent of Native Americans 25 and older hold a bachelor's degree, compared with 24.4 percent of the total population. A total of 26.1 percent of the white population had obtained a bachelor's degree. *See* U.S. Census, *Educational Attainment: 2000*, August 2003, p. 5. Other statistics demonstrate that Native Americans are twice as likely to drop out of high school as the national average. *See* U.S. Department of Education, Indian Nations at Risk Task Force, "Plans for Dropout Prevention and Special School Support Services for American Indian and Alaska Native Students," 1992.

[121] State of Utah, Governor's Office of Planning and Budget, "Utah Data Guide: Income, Poverty, and Education," p. 7.

like the one told by Malcolm Bowekaty, a member of the Pueblo of Zuni and a certified health education specialist, about the impact of diabetes on his family. From all accounts, his story is common in Indian Country. Mr. Bowekaty's entire family—parents, grandparents, aunts, and nieces—all had diabetes in some form. His 70-year-old grandfather developed a foot infection that led to the amputation of both legs below the knee. Mr. Bowekaty recalls how he felt watching his grandfather go through this experience: "I saw my grandfather who grew up ranching, mustang busting, farming—a very tough person—become like a baby. I couldn't stand that."[122]

Undoubtedly, poverty and lack of education contribute to health disparities. These socioeconomic disparities, however, are inextricably linked to racial bias and discrimination.[123] This is especially true for Native Americans. According to the *Women of Color Health Data Book* published by the Department of Health and Human Services (HHS), racism and discrimination have contributed to Native American poverty.[124] Thus, socioeconomic disparities causing health disparities must be viewed in light of racism and discrimination. Efforts to improve the health status of Native Americans must include the elimination of racial bias and discrimination, and the removal of cultural and linguistic barriers.

Health Behaviors and Lifestyle

Many would argue that health status is determined by one's lifestyle and behaviors such as cigarette smoking, heavy alcohol use, and diet. Specifically for Native Americans, there is limited data on behavioral risk factors associated with morbidity and mortality.[125] In the absence of authoritative figures, there is no consensus as to the exact degree to which lifestyle and health behaviors affect health outcomes. Nonetheless, the Indian Health Service reports that "lifestyle and behavioral issues contribute to almost 70% of the diseases that occur at a higher rate in Indian country."[126] Similarly, the *National Healthcare Disparities Report* estimates that "up to 50 percent of health status can be accounted for by health behaviors and only 15 to 20 percent by the health care delivery system."[127]

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[122] Malcolm Bowekaty, "From Science to the Spirit of People," in *Eliminating Health Disparities: Conversations with American Indians and Alaska Natives*, eds. Michael E. Bird, William M. Kane, and Marcia Quackenbush (ETR Associates, 2002), p. 54.

[123] Mary Anne Bobinski, *Health Disparities and the Law: Wrongs in Search of a Right*, 29 AM. J.L. & MED. 363, 373 (2003).

[124] U.S. Department of Human Health Services, National Institutes of Health, Office of the Director, "Women of Color Health Data Book," 2002, p.4, <http://www4.od.nih.gov/orwh/wocEnglish2002.pdf> (last accessed Sep. 29, 2004).

[125] David Pearson et al., "Differences in Sociodemographic, Health Status, and Lifestyle Characteristics Among American Indians by Telephone Coverage," *Preventive Medicine*, vol. 23, 1994, p. 461.

[126] Dr. Charles W. Grim, Indian Health Service, "Eliminating Disparities is More Than an Access Issue" (speech delivered at the 32nd Annual Meeting of the Association of American Indian Physicians, Santa Fe, NM, Aug. 4, 2003), <http://www.ihs.gov/PublicInfo/PublicAffairs/Director/2003_Statements/FINAL-AAIP_August_2003.pdf> (last accessed Feb. 9, 2004).

[127] Institute of Medicine, *Guidance for the National Healthcare Disparities Report* (National Academies Press, Washington, DC, 2002), p. 102.

Other research has found that one's lifestyle and behavioral risks account for only a moderate portion of his or her health status.[128] Furthermore, a report on the health status of Native American males explained that while there is no consensus on the underlying causes for behavioral risks among Native American males, these risk-taking behaviors are likely to have "complex etiologies involving genetic, social, cultural, hormonal and other interactions."[129] The research explained that the increased risk-taking behaviors among Native American males are caused by "loss of cultural identity, anomie, loss of traditional roles for males, failure of primary socialization, and unresolved grief from historical trauma."[130]

This research further supports the notion that while individuals make their own choices in terms of cigarette smoking, alcohol or drug use, and diet, there are underlying factors that affect their choices and life experiences. For example, poverty has led Native Americans to depend on welfare and government commodity foods that are high in fat and calories.[131] While malnutrition was a problem among Native Americans two generations ago, the problem today is obesity.[132] Though obesity is caused by dietary decisions and a lack of physical activity and exercise, the absence of food choices and the lack of education among poor Native Americans regarding healthy diets are major contributors to obesity, which leads to other chronic diseases.[133]

According to Lisa Perkins, director of community health promotion for the Cherokee Nation, many rural areas lack the environment necessary for Native Americans to lead a healthy lifestyle.[134] She explains that because many rural areas do not have more than one general store, the choices in the types of food Native Americans can purchase are limited.[135] Furthermore, specialty food items with lower fat content are often too expensive for poverty stricken rural Native Americans.[136] Moreover, many rural areas do not have fitness centers or even safe places for physical activities.[137] Even worse, many poor Native Americans battle other domestic problems such as domestic violence; thus, eating healthy and exercising is simply not a realistic priority.[138] Ms. Perkins added that the failure to exercise and choose healthy diets is further caused by deep-rooted intergenerational trauma.[139]

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[128] Paula M. Lantz et al., "Socioeconomic Factors, Health Behaviors, and Mortality," *Journal of the American Medical Association,* vol. 279, no. 21, June 3, 1998, pp. 1703–46.

[129] Everett R. Rhoades, "The Health Status of American Indian and Alaska Native Males," *American Journal of Public Health,* vol. 93, 2003, p. 777.

[130] Ibid., p. 777.

[131] U.S. Department of Human Health Services, National Institutes of Health, Office of the Director, "Women of Color Health Data Book," 2002, p.4, <http://www4.od.nih.gov/orwh/wocEnglish2002.pdf> (last accessed Sep. 29, 2004).

[132] Ibid.

[133] Ibid.

[134] Lisa Perkins, director of community health promotion, Cherokee Nation, telephone interview, May 18, 2004.

[135] Ibid.

[136] Ibid.

[137] Ibid.

[138] Ibid.

[139] Ibid.

Confirming the role of intergenerational trauma on behavior and lifestyle decisions, Dr. Everett Rhoades, in his study of the health status of Native American males, found that the lack of cultural identity and unresolved grief from historical trauma contribute to behavioral risks.[140] These deep-rooted social, historical, and cultural factors affect how Native Americans view themselves and how they make choices. To disregard these underlying factors and simply state that Native Americans make their own decisions on cigarette smoking, alcohol or drug use, and diet could be interpreted as blaming the victims.

The disproportionate health outcomes in Native Americans must be understood in the context of social and cultural barriers that also affect socioeconomic status as well as lifestyle and behavioral choices. Any program or initiative aimed at eliminating these health disparities must recognize the predicament facing many Native Americans and appropriately address the barriers that cause disproportionate health outcomes for Native Americans.

Conclusion

There has been tremendous improvement in health outcomes for Native Americans in the past several decades. Nevertheless, Native Americans continue to experience serious health disparities from social and cultural barriers that include lifestyle decisions and socioeconomic status. Health disparities are not simply a product of poverty and inadequate education. Studies have repeatedly shown that even when access-related factors such as insurance coverage and socioeconomic status are controlled, racial and ethnic differences in health care remain.

Perhaps most importantly, this chapter is about race and the uniquely related classifications of ethnic and political status accorded the Indian race. Unfortunately, in this country, race matters when it comes to medical treatment. While much progress has been made to improve access to health care for people of color, studies show that people of color are less likely to receive certain medical procedures. Much of the unfair treatment and mistreatment stem from deeply rooted social inequities. The Commission makes the recommendations below to address these inequities.

Racial bias and discrimination continue to play a role in medical and treatment decisions. As the main health care provider and advocate for Native Americans, IHS has a duty to ensure that IHS and IHS contract service providers deliver health services that are culturally sensitive and free from bias. To ensure that Native Americans are provided this level of health care:

- IHS should create separate complaint processing offices within each IHS facility to monitor, investigate, and resolve complaints alleging bias and discrimination in either IHS facilities or contract health facilities. These offices should report directly to senior management.

- IHS should establish formal review and appeals procedures at the area office level and in headquarters to ensure timely resolution of all discrimination complaints and prompt notification to complainants regarding the status of their complaints.

[140] Everett R. Rhoades, "The Health Status of American Indian and Alaska Native Males," *American Journal of Public Health*, vol. 93, 2003, p. 777.

- IHS, upon creation of its complaint processing offices, should require each office to produce periodic reports summarizing the number of complaints, the nature of the complaints received, and any remedial action taken. Based on analysis of these reports, IHS should formulate appropriate training programs aimed at eliminating bias and discrimination.

- IHS should implement formal cultural training programs aimed at teaching providers to present culturally specific health information and provide culturally appropriate services.

- IHS should implement cultural training programs for non-IHS providers at contract health facilities.

- IHS should, in addition to providing cultural training, expand efforts to hire more Native American providers who can better understand and communicate with Native American patients.

- IHS and other federal agencies, working in partnership together, should create and implement economic development strategies aimed at increasing tribal economic opportunities. These strategies should be tailored to meet the needs of each individual tribe as identified through tribal consultations and sound research.

- IHS should involve Native American communities in collecting and monitoring community health data by partnering Native American communities and tribes with researchers, colleges, universities, and others with technical expertise in health research or Indian health research, in particular.

- HHS should increase the availability of grants to Native American communities for conducting health research and data collection.

- IHS should create and implement a formal policy to ensure that adequate professional language assistance is available at all IHS and non-IHS contract facilities, such as the use of call centers where IHS can provide and direct telephone language translation services.

- IHS should create and make available health information brochures in English and local native languages. These brochures should be distributed through IHS service units.

Chapter 3: Structural Barriers Limiting Native American Access to Health Care and Contributing to Health Disparities

Eliminating structural barriers that limit access to health care is just as critical to providing adequate health care as is eliminating social and cultural barriers such as racial and ethnic bias.[1] The Institute of Medicine's 2003 report affirmed that "access-related factors may be the most significant barriers to equitable care and must be addressed as an important first step toward eliminating health disparities."[2]

There are several structural barriers that limit access to health care for Native Americans. These barriers are found within the actual health care system and include:

- Management or oversight issues relating to different Indian Health Service (IHS) programs.
- Geographic location of facilities.
- Outdated and aging facilities.
- Extended wait times at facilities for treatment.
- Retention and recruitment of qualified providers.
- Misdiagnosis or late diagnosis of diseases.

The availability and accessibility of health care for Native Americans are influenced by the IHS organization and its service delivery system. How IHS services are structured and where those services are provided significantly influence the degree to which Native Americans have access to health care. This chapter explores the structural barriers preventing adequate access to quality health care.

Introduction to the Indian Health Service

As explained in the introductory chapter, the federal government's obligation to provide health services to Native Americans originated in treaty obligations to the Native American tribes. To fulfill specific treaty obligations to select tribes, the federal government began providing limited health services, including hospitals, physicians, medical supplies, and housing for physicians.[3] It was not until 1832 that Congress began appropriating funds for health programs for all Native Americans. At that time, Congress began funding a smallpox vaccination program for tribes deemed friendly to the United States and to individuals who, if they contracted smallpox, would pose a health threat to non-Native Americans in or near military

[1] U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, *National Health Disparities Report*, December 2003, p. 107.

[2] Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (National Academies Press, Washington, DC, 2002), p. 33 (hereafter cited as IOM, *Unequal Treatment*).

[3] Jennie R. Joe, "The Rationing of Healthcare and Health Disparity for the American Indians/Alaska Natives," in *Unequal Treatment: Conforming Racial and Ethnic Disparities in Health Care*, ed. National Academy of Sciences, 2002, p. 531 (hereafter cited as Joe, "The Rationing of Healthcare").

outposts.[4] The federal government also sought to assimilate Native Americans into the general population by emphasizing Western medicine over traditional healing practices.

In 1849, the Office of Indian Affairs, now the Bureau of Indian Affairs (BIA), took over health care responsibilities from the War Department. In 1954, Congress transferred the health responsibility from BIA to the Department of Health, Education, and Welfare, now known as the Department of Health and Human Services (HHS). The Indian Health Service was created within HHS in 1955 and assumed responsibility for providing health services to Native Americans. The goal of IHS is to raise the health status of Native Americans to the highest possible level.[5]

Since its inception in 1955, IHS has provided health services to eligible Native Americans from federally recognized tribes. The IHS is the principal federal health care provider and health advocate for Native Americans. All Native Americans seeking IHS services must first meet eligibility criteria.[6] Once the eligibility requirements are met, applicants do not need to establish economic need to receive services.[7] However, because the eligibility requirements limit IHS services to members of federally recognized tribes, some Indian health advocates argue that the requirements are established to exclude and not to extend health care to Native Americans.[8]

From the IHS perspective, however, establishing firm eligibility requirements is necessary to meet the demand for services in light of limited resources.[9] IHS provides health care services to approximately 1.6 million of the 2.6 million Native Americans in the United States.[10]

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[4] Joe, "The Rationing of Healthcare," p. 531.

[5] Indian Health Service, "Indian Health Service Introduction," <http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/IHSintro.asp> (last accessed Mar. 23, 2004). The mission of IHS is "to raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level." Ibid.

[6] IHS services are provided to (1) an individual of Indian or Alaska Native descent; (2) an Indian of Canadian or Mexican origin, recognized by an Indian tribe or group as a member of an Indian community served by the Indian Health program; (3) a non-Indian woman pregnant with an eligible Indian's child for the duration of her pregnancy through post partum (usually six weeks); or (4) a non-Indian member of an eligible Indian's household and the medical officer in charge determines that services are necessary to control a public health hazard or an acute infectious disease which constitutes a public health hazard.

A person is of Indian or Alaska Native descent as evidenced by one or more of the following factors: (1) is regarded by the community in which he lives as an Indian or Alaska Native; (2) is a member, enrolled or otherwise, of an Indian or Alaska Native Tribe or Group under federal supervision; (3) resides on tax-exempt land or owns restricted property; (4) actively participates in tribal affairs; (5) any other reasonable factor indicative of Indian descent.

Indian Health Service, "Indian Health Manual," <http://www.ihs.gov/PublicInfo/Publications/IHSManual/Part2/pt2chapt1/pt2chapt1.htm#212> (last accessed July 15, 2003).

[7] The National Academy of Sciences, *Changing Numbers, Changing Needs: American Indian Demography and Public Health*, 1996, p. 290.

[8] Ibid. *See also* Ralph Forquera, *Urban Indian Health* (Henry J. Kaiser Family Foundation, November 2001), p. 8 (hereafter cited as Forquera, *Urban Indian Health*); Delight Satter, M.P.H., research scientist, UCLA Center for Health Policy Research, and director, American Indian and Alaska Native Research Program, telephone interview, July 1, 2003.

[9] *See* Betty Pfefferbaum et al., *Providing for the Health Care Needs of Native Americans: Policy, Programs, Procedures, and Practices*, 21 AM. INDIAN L. REV. 211, 248 (1997) (hereafter cited as Pfefferbaum, *Providing for the Health Care Needs of Native Americans*).

[10] Indian Health Service, "Indian Health Service Introduction," <http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/IHSintro.asp> (last accessed July 15, 2003).

These recipients are members of more than 560 federally recognized tribes in 35 states.[11] IHS provides services primarily to the Native Americans living on or near reservations in rural areas. For those 1 million Native Americans who do not meet the eligibility criteria, this eligibility requirement is a major contributor to lack of access to health care.

IHS Health Delivery Programs: Direct, Tribal, Urban Indian

The IHS is not a health insurance program; rather, it is a federally funded service, providing health care services to eligible Native Americans.[12] According to IHS Director Dr. Charles Grim, it is a program of "universal eligibility but limited availability."[13] Funds for IHS health care are discretionary, not a personal entitlement.[14] Consequently, IHS provides health care services only to the extent appropriated funding allows. In addition to its health services role, IHS is the principal health advocate for Native Americans.[15] Accordingly, it collaborates with federal entitlement programs, state or local health care programs, and private insurance providers to ensure that adequate care is funded and provided.

IHS is made up of 12 regional administrative units called "area offices," as shown in Figure 1, and these area offices oversee the operation of IHS programs. Each area office provides administrative support such as distributing funds, monitoring programs, evaluating activities, and providing technical support to the hospitals, clinics, and other facilities within its region.[16]

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[11] Indian Health Service, "Indian Health Service Introduction," <http://www.ihs.gov/publicinfo/publicaffairs/welcome%5Finfo/ihsintro.asp> (last accessed Oct. 3, 2003). *See also* Indian Entities Recognized and Eligible to Receive Services from the United States Bureau of Indian Affairs, Notice, 67 Fed. Reg. 46,328 (July 12, 2002).

[12] The National Academy of Sciences, *Changing Numbers, Changing Needs: American Indian Demography and Public Health*, 1996, p. 290.

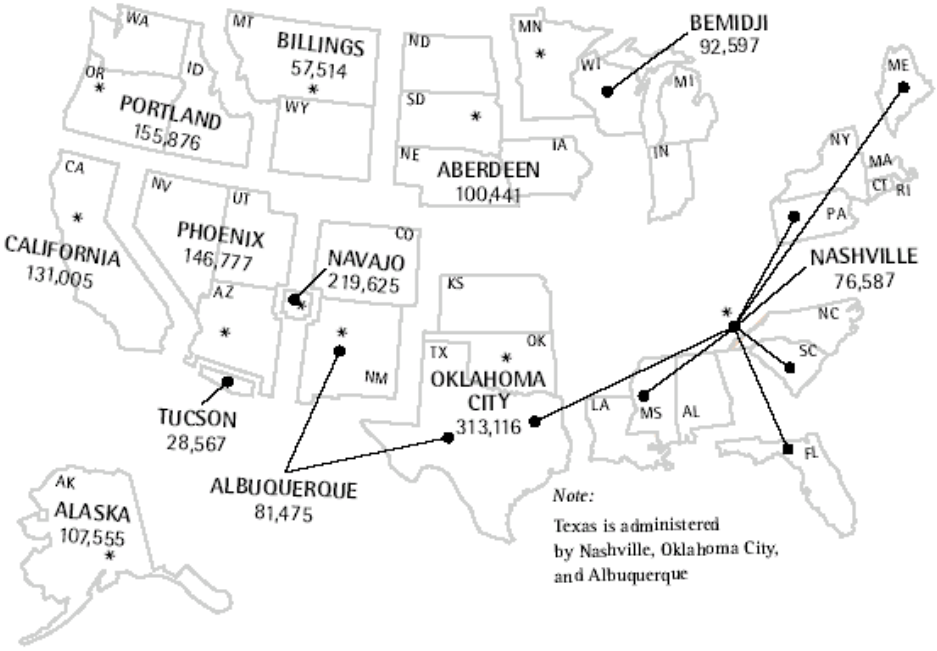
[13] Dr. Charles W. Grim, testimony before the U.S. Commission on Civil Rights, briefing, Albuquerque, NM, Oct. 17, 2003, transcript, p. 104 (hereafter cited as Briefing Transcript).

[14] As discussed below in the sections on barriers to health insurance, there is a widely held perception among Native Americans that they are entitled to health care based on their unique relationship and history with the federal government. Related, in part, to this historical view is a vigorous debate as to whether Native American health care should become a formal government "entitlement program." Those in favor see entitlement status as a means of enforcing sufficient funding to fully meet federal health care obligations. Those opposed see entitlement as a potential ceiling for individual services and a potential loss of bargaining position as the federal obligation becomes enforceable only by individuals rather than the tribes. *See* Myra Munson, partner, Sonosky, Chambers, Sachse, Miller & Munson, telephone interview, Aug. 11, 2003; Ed Fox, executive director, Northwest Portland Area Indian Health Board, telephone interview, Aug. 14, 2003.

[15] Indian Health Service, "Indian Health Service Introduction," <http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/IHSintro.asp> (last accessed July 15, 2003).

[16] Indian Health Service, "Indian Health Service Area Map," <http://www.dsfc.ihs.gov/ihsmap.cfm> (last accessed Mar. 18, 2004); U.S. Department of Health and Human Services, *Fiscal Year 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-25. (hereafter cited as HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*).

Figure 1: Indian Health Service—Service Population by Area



Source: Indian Health Service, *Trends in Indian Health 1998–99*, <http://www.ihs.gov/publicinfo/publications/trends98/part2.pdf> (last accessed Aug. 21, 2003).

Within the 12 regional area offices are 153 basic local administrative units called service units.[17] A service unit is an administrative entity, operated by either IHS or a contracting tribe, that has the responsibility for planning, managing, and evaluating the health programs in its jurisdiction.[18] It serves a defined geographic area smaller than that for which an area office is responsible and is usually centered on a single federal reservation or, in Alaska, a population concentration.[19]

Within the 153 local administrative units, or service units, are 594 direct health care delivery facilities, including 49 hospitals; 231 health centers; five school health centers; and 309 health stations, satellite clinics, and Alaska village clinics.[20] Within this system, Indian tribes deliver IHS-funded services to their own communities with just over 50 percent of the IHS budget in 15 hospitals, 172 health centers, three school health centers, and 260 health stations and Alaska village clinics.[21] For those tribes that have elected to have IHS administer their health

[17] Indian Health Service, Office of Public Health, *Regional Differences in Indian Health 2000–2001* p. 4 (hereafter cited as IHS, *Regional Differences*).

[18] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-17; *see also* U.S. Department of Health and Human Services, Public Health Service, Indian Health Service, *Indian Health Service Circular ND. 88-2*.

[19] Ibid.

[20] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-15.

[21] Ibid.

services, IHS provides direct services at 36 hospitals, 59 health centers, two school health centers, and 49 health stations.[22]

The IHS-funded services are delivered in three ways: direct IHS services, tribal services, and Urban Indian Health Programs. These services are provided only to those qualified Native Americans who meet IHS eligibility criteria. For those qualifying, health services are delivered directly at IHS facilities, through tribally contracted and operated health programs, or at IHS contract health service facilities.[23] In addition, 34 Urban Indian Health Programs provide limited health and referral services to approximately 150,000 Native Americans living in cities throughout the country.[24] Each of the three delivery programs is discussed below, starting with direct delivery system and tribal health programs. As these two programs utilize and rely on the Contract Health Services (CHS) program to provide services unavailable at IHS and tribal facilities, a discussion of the CHS program follows. Urban Indian Health Programs are discussed last.

Direct Delivery System

The IHS direct care delivery system consists of hospitals, health centers, health stations, and residential treatment centers.[25] Federal employees in the Indian Health Service provide health care services in 63 IHS-operated service units, administering 36 hospitals and 59 health centers, two school health centers, and 49 health stations.[26] Most IHS hospitals also have active outpatient departments that provide dental, mental health, and other services.[27] IHS-operated facilities will expend $674 million or 46 percent of the FY 2004 budget appropriated for non-contract services.

Health centers are facilities physically separate from hospitals. They offer a complete range of ambulatory services (including primary care physicians, nursing, pharmacy, laboratory, and radiology services) for a minimum of 40 hours per week.[28] By comparison, health stations are often smaller mobile units, which offer fewer outpatient services for less than 40 hours per week. Mid-level practitioners usually provide primary care, with physician care available on a regularly scheduled basis.[29]

In general, IHS direct services are limited in the scope of services provided in comparison to non-IHS facilities. Typically, IHS hospitals are smaller and have fewer beds than other U.S. community hospitals. Aside from the three large IHS hospitals—the Alaska Native

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[22] Ibid.

[23] Indian Health Service, "Fact Sheet," <http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/ThisFacts.asp> (last accessed Sept. 4, 2003) (hereafter cited as IHS, "Fact Sheet").

[24] Ibid; Joe, "The Rationing of Healthcare, " p. 534. Currently, only about 38 percent of Native Americans live on federal trust lands; the remainder resides in off-reservation or urban communities. Joe, "The Rationing of Healthcare, " p. 529.

[25] IHS, "Fact Sheet."

[26] IHS, *Regional Differences*, p. 4.

[27] Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, pp. 211, 233.

[28] IHS, *Regional Differences*, p. 13.

[29] Indian Health Service, "IHS Glossary of Terms," <http://www.ihs.gov/aboutihs/thisglossary.asp> (last accessed Dec. 30, 2003).

Medical Center in Anchorage, Alaska; the Gallup Indian Medical Center in Gallup, New Mexico; and the Phoenix Indian Medical Center in Phoenix, Arizona—IHS hospitals have fewer than 50 beds and most are without surgical or obstetric services, compared with an average of 73 beds for all rural hospitals and 223 beds for all urban hospitals nationally.[30] In addition, IHS hospitals provide limited inpatient services and fewer high-tech services.[31]

Over time, IHS has shifted from inpatient care to more ambulatory care services, a move that follows the national trend.[32] New medical and diagnostic procedures and other technological advances have allowed more services to be delivered on an outpatient basis.[33] According to the most recent *Trends in Indian Health* report by IHS, the average daily inpatient load for IHS, tribal, and contract general hospitals declined by 58 percent from 2,353 in 1980 to 981 in 1997; ambulatory medical visits increased 309 percent during the same period.[34]

Despite IHS efforts to meet the health care needs of Native Americans, limited funding has led to the rationing of services.[35] Rationing affects direct and tribal programs, however, it most severely affects contract health services as discussed in detail in the section on the Contract Health Services program.

As detailed below, IHS contracts with non-IHS providers to provide health services where services are not available through IHS direct delivery or tribal programs.[36] The IHS relies on the Contract Health Services program to provide complicated services to many widespread and remote areas with small populations.[37] The annual funding for CHS increased 27 percent from FY 1998 to FY 2003. As IHS uses more of its resources for contract services, fewer resources are available for IHS direct services, making it more difficult to develop and improve these services.[38]

Despite a lack of resources that limits both quantity and quality of IHS-provided health care, there are advantages to a federally operated system. First, the direct delivery system does bring services to remote Indian reservations where market conditions would otherwise prevent

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[30] Joe, "The Rationing of Healthcare," p. 534; U.S. Department of Health and Human Services, Office of Inspector General, *Hospital Closure: 1998*, July 2000, p. 1.

[31] Joe, "The Rationing of Healthcare," pp. 534–35; Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 234.

[32] Jim Cussen, chief executive officer, Claremore Indian Hospital, written response to USCCR questions, May 27, 2004; Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 234. *See generally* South Carolina Hospital Association, "Glossary," <http://www.bluecrossca.com/bus_units/lgrp/50plus_Glossary.htm> (last accessed Sept. 30, 2003). Ambulatory care services are defined as "[s]ervices rendered to persons not confined overnight, including emergency, clinical, laboratory, radiology and home health services. Often referred to as 'outpatient' services." Ibid.

[33] Joachim Roski and Rebecca Gregory, "Performance Measurement for Ambulatory Care: Moving Towards a New Agenda," *International Journal for Quality in Health Care*, vol. 13, 2001, p. 447.

[34] IHS, *Trends in Indian Health*, pp. 174–75, 200–01, 226.

[35] Craig Vanderwagen, M.D., acting chief medical officer, Indian Health Service, interview in Rockville, MD, July 21, 2003. *See also* Roanhorse Testimony, Briefing Transcript, p. 169.

[36] IHS, "Fact Sheet."

[37] Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 235.

[38] Ibid.

the delivery of health services.[39] The frequent closure of rural hospitals and a decreasing number of providers who leave rural areas to join managed care organizations elsewhere are among the factors that make it more difficult for rural residents to access health services.[40]

Furthermore, many small tribes lack the resources and expertise to provide or manage care on their own; IHS direct service brings health care facilities and services to often remote reservations.[41] In short, IHS brings both resources and expertise.[42] The ability of the federal government to provide federal benefits (of greater value than the tribes can afford to pay) and therefore recruit more and better qualified individuals is one reason some tribes choose not to enter into self-governance, or compacting, agreements to operate their own health programs.[43] In addition, as long as the government is providing care there is less fear that all funding will be withdrawn. As the tribes take over, some fear that the federal government will use that as motivation to back out of its obligation to pay.[44]

Second, while disparities still exist, the health status of Native Americans has improved.[45] Several sources familiar with Native American health care issues agree that IHS has done a remarkably good job considering formidable obstacles and limited funding.[46] Since 1973, mortality rates have declined for the following: tuberculosis (82 percent); maternal deaths (78 percent); infant deaths (66 percent); accidents (57 percent); injury and poisoning (53 percent); and pneumonia and influenza (50 percent).[47]

Despite the noted improvements and advantages of the direct IHS delivery system, health disparities continue to disproportionately affect Native Americans. The latter sections of this chapter explore the specific factors that affect access to quality care. As will be established, both the direct and tribal delivery systems are plagued with problems that must be addressed to reach the goal of eliminating health disparities affecting Native Americans.

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[39] Lyle Jack, tribal councilman, Oglala Sioux Tribe, telephone interview, Oct. 23, 2003.

[40] U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, "Research in Action: Improving Health Care for Rural Populations," <http://www.ahrq.gov/research/rural.htm> (last accessed Apr. 5, 2004).

[41] Michael Bird, interview in Washington, DC, Apr. 6, 2004.

[42] Jack interview.

[43] Taylor McKenzie, former vice president, Navajo Nation, telephone interview, Sept. 11, 2003. *See* the "Tribal Health Programs" section for a detailed discussion of self-governance agreements.

[44] *See* Joe, "The Rationing of Healthcare," p. 544.

[45] *See* Perez Testimony, Briefing Transcript, p. 15. Indian Health Service, *Trends in Indian Health 1998–99*, <http://www.ihs.gov/publicinfo/publications/trends98/part2.pdf> (last accessed Aug. 21, 2003) (hereafter cited as IHS, *Trends in Indian Health 1998–99*). *See also* Perez Testimony, Briefing Transcript, pp. 14, 15.

[46] Jennifer Giroux, M.D., Indian Health Board of Minneapolis, health care policy research and administrative fellow, Center for American Indian and Minority Health, University of Minnesota, telephone interview, July 23, 2002; Jennie Joe, Ph.D., M.P.H., R.N., professor, Family and Community Medicine, University of Arizona School of Medicine, telephone interview, June 24, 2003; J.T. Petherick, executive director, National Indian Health Board, telephone interview, July 2, 2003; Delight E. Satter, M.P.H., research scientist, UCLA Center for Health Policy Research, director, American Indian and Alaska Native Research Program, telephone interview, July 1, 2003.

[47] *See* Perez Testimony, Briefing Transcript, pp. 14–15. IHS, *Trends in Indian Health 1998–99*. *See also* Perez Testimony, Briefing Transcript, pp. 14, 15.

Tribal Health Programs

In addition to IHS direct services, the Indian Self-Determination and Education Assistance Act (referred to as the Self-Determination Act), as amended, allows tribes to contract or compact to provide health care services to their tribal members.[48] The tribes can contract or compact with the federal government to plan, conduct, and administer programs that are authorized under Section 102 of the act.[49] Today, IHS administers self-determination contracts under Title I and self-governance compacts under Title V. A self-determination contract is a contract, grant, or cooperative agreement entered between a tribal organization and IHS for the planning, conduct, and administration of programs or services that are otherwise provided to Indian tribes.[50] A self-governance compact is a legally binding and mutually enforceable written agreement that affirms the government-to-government relationship between a self-governance tribe and the United States.[51] Under a Title I contract, a tribal organization contracts to conduct and administer certain portions of a health program operated by IHS. Under a Title V compact, on the other hand, a tribal government compacts to take over the operation of a health program.

Congress first enacted the Self-Determination Act in 1975 to further the goal of Native American self-determination by ensuring maximum Native American participation in the management of federal programs and services for Native Americans.[52] The act authorizes tribes to take over the management and administration of programs through contractual arrangements with the agencies that previously administered them.[53] Under the act, tribes receive funding for the programs they contract or compact to manage and operate. The IHS and the Bureau of Indian Affairs are two federal agencies that enter into "self-determination contracts" with tribes.

The self-governance programs, created pursuant to the Self-Determination Act, were designed to provide tribal governments with more control and decision-making authority over the day-to-day operation of programs providing services to Native Americans. The Self-Determination Act also promotes the government-to-government relationships referenced in the Constitution. Where tribes choose not to contract or compact for health programs, IHS continues to provide health services to the tribes.[54] While some tribes have chosen to continue receiving

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[48] Indian Self-Determination and Education Assistance Act of 1975, Pub. L. No. 93-638, 88 Stat. 2203 (codified as amended in scattered sections of 25 U.S.C.). Under this law, tribes can contract with the federal government to take over the management of all or part of their health care programs; subsequent amendments allowed tribes to compact with the federal government to obtain more power and independence in the management of their health programs. In 1992, the Self-Determination Act was reauthorized through amendments to IHCIA. *See* Indian Self-Determination Act of 1992, Pub. L. No. 102-573, Title VIII §813(a), 106 Stat. 4590 (codified as amended in scattered sections of 25 U.S.C.).

[49] 25 U.S.C.S. §§ 450 *et seq*. (2000).

[50] 25 U.S.C. § 450b(j) (1994).

[51] 42 C.F.R. § 137.30 (2004).

[52] Indian Self-Determination and Education Assistance Act of 1975, Pub. L. No. 93-638, 88 Stat. 2203 (codified as amended in scattered sections of 25 U.S.C.).

[53] *Id.*

[54] It is important to recognize that the decision to continue to rely on IHS for health services "is as legitimate a self-governance decision as that of a tribe that chooses to operate the program themselves." Munson Testimony, Briefing Transcript, p. 252.

health care services directly from IHS, more tribes are taking on the management and delivery of health care.[55]

In 1988, Congress amended the Self-Determination Act through the enactment of the Tribal Self-Governance Demonstration Project Act.[56] Under the 1988 demonstration project, tribes first began compacting BIA programs. The tribal compacts under the demonstration project greatly expanded with the passage of the Tribal Self-Governance Demonstration Project Act of 1991.[57] In 1992, the demonstration project was extended to include 30 tribes within IHS.[58] The Demonstration Project Act simplified the self-determination contracting processes and facilitated the assumption of IHS programs by tribal governments. The act also authorized the transfer of IHS program funds that would have been spent by IHS to tribes under a compacting process. Title III of the Self-Determination Act, under the Demonstration Project Act, authorized the signing of self-governance compacts for a specific number of tribes that meet certain criteria.[59] In 1994, the self-governance demonstration project became permanent for Department of the Interior programs.[60] In 2000, under Title V of the Self-Determination Act, the self-governance programs at IHS became permanent.[61]

Since IHS began its first Title III compact negotiations under the demonstration project in May 1993, IHS has gradually increased the self-governance compacts; by 1998, IHS had entered into 39 self-governance compacts and 55 annual funding agreements.[62] Currently, there are 61 self-governance tribal compacts and 81 funding agreements representing 285 tribes and providing health services to more than 51 percent of the tribes.[63] During FY 2003, $796 million of the $1.47 billion appropriated to IHS for non-contract services was transferred to the tribes

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[55] Joe, "The Rationing of Healthcare," p. 534.

[56] The Tribal Self-Governance Demonstration Project Act mandated that the Secretary of the Department of the Interior (DOI) select 20 tribes, for the period of five years, to plan, conduct, consolidate, and administer programs, services, and functions previously administered by DOI. *See* Pub. L. No. 10-472, 102 Stat. 2285 (1988) (codified as amended in 25 U.S.C. § 450f note). The project required DOI to negotiate and to enter into an annual written funding agreement with the participating tribes. This funding agreement allowed the participating tribal governments to "redesign programs, activities, functions or services and to reallocate funds for such programs, activities, functions or services." *Id*.

[57] *See* Tribal Self-Governance Demonstration Project Act, Pub. L. No. 102-184, §1, 105 Stat. 1278 (repealed at 25 U.S.C.S. §§ 458aaa *et. seq*. (2000)). National Indian Health Board, *Tribal Perspectives on Indian Self-Determination and Self-Governance in Health Care Management*, 1998, p. 4 (hereafter cited as NIHB, *Tribal Perspectives*).

[58] *See* Indian Health Amendments of 1992, Pub. L. No. 102-573, Title VII, § 814, 106 Stat. 4590 (1992) (codified as amended in 25 U.S.C. § 450f).

[59] Before a tribe can enter into a self-governance compact, it must first successfully complete three years of tribal management under self-determination contracts. 25 U.S.C. § 458bb(c)(3).

[60] Tribal Self-Governance Act of 1994, Pub. L. No. 103-413, Title II, 108 Stat. 4270 (1994) (codified as amended in 25 U.S.C. §§ 450 note, 458aa to 458hh).

[61] Tribal Self-Governance Amendments of 2000, Pub. L. No. 106-260, Title V, 114 Stat. 711 (codified as amended in scattered sections in 25 U.S.C.).

[62] *Tribal Self-Governance Amendments of 1998: Hearing on H.R. 1833 Before the Senate Indian Affairs Committee*, 105th Cong. (1998) (testimony of Luana Reyes, director of headquarters operations, Indian Health Service, U.S. Department of Health and Human Services).

[63] Indian Health Service, Office of Tribal Self-Governance, "Purpose and Method of Operation," <http://www.ihs.gov/NonMedicalPrograms/SelfGovernance/index.asp> (last accessed Sept. 22, 2003).

under these programs.[64] In recent years, the total funding administered under Title I contracts and Title V compacts has doubled and the scope of services managed and provided by tribal programs has expanded proportionately.[65]

Historically, tribes first began assuming control of community services and then expanded into medical care.[66] Today, almost all Community Health Representative programs[67] and community-based components of the alcohol programs are tribally operated.[68] The number of tribally operated hospitals has risen; tribes now manage over 20 percent of IHS-funded hospitals. The number of ambulatory medical facilities managed by tribes has also increased. Native American tribes now manage 13 hospitals, 172 outpatient health centers, 176 village clinics in Alaska, 84 health stations, and three school health programs.[69]

While both Title I contracts and Title V compacts are tribally operated programs, they differ in the level of IHS' overall role and oversight. Under the Self-Determination Act, IHS is required to provide technical assistance to tribes in developing Title I contract proposals and to oversee the contracts once they are awarded.[70] Under Title I contracts, IHS also makes field visits to oversee the operation of the contracted programs.[71] Although these tribally operated facilities are intended to promote tribal self-governance, IHS considers Title I contracted tribal programs as extensions of IHS, and thus, they are not independent.[72] Under the Title I contracts, IHS provides technical assistance, helps prospective tribal contractors develop applications, and assumes responsibility, oversight, and control of these tribally operated health care services.[73]

Unlike Title I self-determination contracts, where tribes take over and manage existing health programs without making substantial programmatic changes, under the Title V self-governance compacts, tribes exercise more independence and flexibility in the management and operation of their health programs. Title V compacts allow tribes more flexibility in reprioritizing or changing the health programs to meet what they perceive to be the most urgent

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[64] Ibid. *See also* U.S. Department of Health and Human Services, "FY 2004 Budget in Brief," <http://www.hhs.gov/budget/04budget/fy2004bib.pdf> (last accessed July 14, 2003) (hereafter cited as HHS, "FY 2004 Budget in Brief").

[65] U.S. Department of Health and Human Services, Indian Health Service, "Self-Determination," p. supp-59, <http://www.ihs.gov/AdminMngrResources/Budget/downloads/FY_2001/Sd.PDF> (last accessed Mar. 25, 2004).

[66] Ibid.

[67] The Community Health Representative Programs are tribally administered outreach programs. They are based on the concept that Native American community members, trained in the basic skills of health care provision, disease control, and prevention, can successfully create change in community acceptance and utilization of Western health care resources. Community Health Representatives are Native people well positioned within their communities to provide the needed education and related services that can result in healthier lifestyles and early treatment. U.S. Department of Health and Human Services, Indian Health Service, "Community Health Representatives," <http://www.ihs.gov/adminmngrresources/budget/old_site/cj2002/svcs web docs/communityhealth representatives.doc> (last accessed June 1, 2004).

[68] U.S. Department of Health and Human Services, Indian Health Service, "Self-Determination," p. supp-59, <http://www.ihs.gov/AdminMngrResources/Budget/downloads/FY_2001/Sd.PDF> (last accessed Mar. 25, 2004).

[69] IHS, *Regional Differences*, p. 17; U.S. Department of Health and Human Services, Indian Health Service, Response to the Commission's Interrogatory 5, April 2004 (hereafter cited as IHS, Interrogatory Response).

[70] Indian Self-Determination and Education Assistance Act; IHS, Interrogatory Response 39.

[71] Indian Self-Determination and Education Assistance Act; IHS, Interrogatory Response 39.

[72] Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, pp. 211, 237.

[73] Ibid., p. 237.

health care needs in their communities.[74] Before a tribe can qualify to compact its health programs, it must have successfully completed tribal management under self-determination contracts for a period of three years.[75] A qualified tribe may apply and take over a health program under a Title V compact through negotiation with IHS under less restrictive terms and with more significant options.[76] The only oversight of compacts comes in the form of annual financial audits applicable to both Title I contracts and Title V compacts.[77] Compacting, created in response to criticisms that IHS oversight over tribal programs was excessive, promotes and supports tribal initiative.[78] Compacting also gives more authority to the tribes and reduces IHS bureaucracy.[79]

More specifically, before a tribe can redesign programs or reallocate funds under Title I self-determination contracts, the tribe must obtain IHS approval.[80] Under the present self-governance compact, the tribe has the flexibility to redesign programs to better address its local needs and to transfer funds from one budget category to another without the approval of IHS.[81] The flexibility of the self-governance compact enhances the effectiveness of tribally operated programs.[82] Furthermore, the tribe's ability to redesign its program without IHS approval reduces bureaucracy.[83]

For example, the tribal programs in the Bristol Bay Area Health Corporation in Alaska reduced IHS bureaucracy and increased tribal autonomy. While IHS set the standards and measures to evaluate tribal programs, under the self-governance compact, the corporation jointly developed more relevant and less burdensome baseline measurements for the annual evaluation of its programs.[84] The corporation's autonomy over its health program has also expanded, as it is no longer required to follow the regulations applicable to self-determination contracts, which it had interpreted as micromanagement of internal operations.[85] Under the self-governance compact, the corporation now operates more efficiently and effectively.[86] The corporation has full control over its contract funds by receiving the funds at the beginning of the contract year. It no longer needs to obtain IHS approval for payment of contract funds that the self-determination contracts required. Under the self-determination contracts, IHS disperses portions of the contract funds throughout the year based on agency approval. Self-governance compacts have had a

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[74] Ibid.

[75] 25 U.S.C. § 458bb(c)(3).

[76] IHS, Interrogatory Response 39.

[77] Ibid.

[78] Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, p. 237.

[79] Ibid.

[80] *To Amend the Indian Self-Determination and Education Assistance Act to Provide for Further Self-Governance by Tribes: A Hearing on Title V and Title VI of H.R. 1833 before the Senate Indian Affairs Committee*, 105th Cong. (1998) (testimony of Robert J. Clark, president/CEO, Bristol Bay Area Health Corporation).

[81] Ibid.

[82] Ibid.

[83] Ibid.

[84] Ibid.

[85] Ibid.

[86] Ibid.

dramatic impact on tribal health programs in Alaska.[87] Today, Alaska Natives operate almost the entire IHS health care delivery system in Alaska.[88]

Another advantage of tribal self-governance has been an increase in the number of Native American employees. Consequently, the knowledge gained of specific techniques and the general importance of health remains in the community, building a foundation or "corporate knowledge" that might otherwise have rotated to other communities with the transfer of Public Health Service employees.[89] Employees' earnings, as well, usually remain in the community, providing economic stimulus.[90]

As tribes take over the management and operation of their health programs, the quality of care provided improves by being more responsive to local needs.[91] Tribes participating in the self-governance program say it has significantly improved the health and well-being of their tribal members.[92] Through the administration and management of their own health programs, tribes have more flexibility to tailor programs to meet the specific needs of their tribal members.[93] Therefore, federal funds are more effectively and efficiently used to address the local health needs of Native Americans.[94]

Finally, tribal control creates two financial gains for health care. First, the tribes become more efficient at third-party recovery because they recognize the direct increase in the amount of money available for the purchase of additional health services.[95] Second, the tribes have become willing to seek out private and public grants, knowing that their share of IHS funding will not be reduced as a result.[96]

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[87] Ibid.

[88] Ibid.

[89] Munson interview.

[90] Ibid. For example, in South Dakota Native American health care infuses $170 million into the local economy with an overall impact in excess of $512 million. *See* David Melmer, "Health Care—A State Issue," *Indian Country Today*, vol. 23, no. 26, Dec. 10, 2003, p. 1.

[91] U.S. Department of Health and Human Services, Indian Health Service, Office of Tribal Self-Governance, "Purpose and Method of Operation," pp. 539–40, <http://www.ihs.gov/NonMedicalPrograms/Self Governance/index.asp> (last accessed Mar. 25, 2004); *see also* Joe, "The Rationing of Healthcare."

[92] U.S. Department of Health and Human Services, Indian Health Service, Office of Tribal Self-Governance, "Purpose and Method of Operation," <http://www.ihs.gov/NonMedicalPrograms/SelfGovernance/index.asp> (last accessed Mar. 25, 2004); *Draft Legislation to Reauthorize the Indian Health Care Improvement Act of 1976: A Hearing Before the Senate Indian Affairs Committee*, 106th Cong. (2000) (testimony of H. Sally Smith, chairperson, National Indian Health Board).

[93] U.S. Department of Health and Human Services, Indian Health Service, Office of Tribal Self-Governance, "Purpose and Method of Operation," <http://www.ihs.gov/NonMedicalPrograms/SelfGovernance/index.asp> (last accessed Mar. 25, 2004).

[94] Ibid.

[95] Third-party recovery is the reimbursement of IHS by other health care providers obligated to pay for health services. Typically, these providers include, Medicare, Medicaid and private insurance companies. By law, IHS is the payor of last resort. A more detailed discussion is provided in Chapter 4.

[96] Munson interview.

Generally, the shift toward tribal autonomy in health care under the self-governance agreements has been a dramatic success.[97] Tribes have redirected resources based on local priorities and needs, resulting in more effective use of those resources.[98] Because tribes have full control over their programs and are less restricted by IHS regulations, they are able to consolidate and redesign health programs to meet the needs of their own tribal members. Virtually every tribe that has taken control of health facilities has expanded services.[99] The following paragraphs relate some tribal experiences confirming this success.

The Cherokee Nation was one of the first self-governance compacting tribes under the demonstration project. In every service category, the Cherokee Nation has expanded the services since taking over.[100] It has developed partnerships with state and local governments as well as private entities, including nearby teaching universities, to expand and diversify its services.[101] According to Chris Walker, executive director of the Cherokee Nation Health Services, the Cherokee Nation has maximized its resources to expand and create more services for its tribal members through various partnerships, third-party collections, and reallocation of its IHS funding, as well as its tribal funds.[102]

According to the director of health of the Wampanoag Tribe of Gay Head, tribal operation of its health program has allowed the tribe more flexibility and autonomy to create solutions to the health problems confronting its community.[103] Furthermore, the tribe has gained full control of its funding by receiving it from IHS at the beginning of each fiscal year.[104]

Since the Alamo Navajo Chapter, a political subdivision of the Navajo Nation, began contracting small portions of IHS health care activities 25 years ago, it has seen growth in facilities and staff.[105] According to Bob Newcombe, the health services division director of the Alamo Navajo School Board, the Indian Self-Determination Act has "created a greater level of sophistication and health capacity building in Indian Country than existed two decades ago."[106]

The Shoshone-Paiute Tribes of the Duck Valley Indian Reservation, after nearly losing accreditation of its facility in the first two years of tribal operation because it did not receive

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[97] Paula Williams, Indian Health Service, interview in Washington, DC, Sept. 8, 2003; Dorothy Dupree, Centers for Medicare & Medicaid Services, telephone interview, June 30, 2003; Don Kashevaroff, Alaska Native Tribal Health Consortium, telephone interview, Sept. 3, 2003.

[98] *On legislation relating to Native Health Care: A briefing on S. 299 and S. 406 before the Senate Indian Affairs Committee*, 106th Cong. (1999) (testimony of Chris Walker, executive director, Cherokee Health Services; Melanie Knight, Government Resources, Cherokee Nation; and W. Ron Allen, Jamestown S'Klallam Tribe).

[99] NIHB, *Tribal Perspectives*; Walker interview; Knight interview; Munson interview.

[100] Chris Walker, executive director, Cherokee Health Services, interview in Washington, DC, Apr. 23, 2004.

[101] Ibid.

[102] Ibid.

[103] Freddy Rundlet, director of health, Wampanoag Tribe of Gay Head, e-mail response to USCCR questions, Apr. 29, 2004.

[104] Ibid. An added benefit is the ability to earn interest on those funds throughout the year.

[105] Bob Newcombe, health services division director of the Alamo Navajo School Board, Inc., e-mail response to USCCR questions, May 3, 2004.

[106] Ibid.

contract support payments, tripled third-party collections and stabilized its physician staffing.[107] It no longer has IHS providers rotate through on a short-term basis and it is fully staffed with over a dozen more positions than when IHS ran the facility.[108] The tribes' health facility is evaluating the possibility of adding a third dental operatory and technology such as a CT scanner to better serve its beneficiaries.[109]

According to Bill Elliot, health director of the Fallon Paiute Shoshone Tribe, after having worked for four tribes, he has found that "by far, self-governance provides the tribe with better services, more services, and services which are cost effective and more efficient."[110] The Yerington Paiete Tribe took over an IHS program that offered care only three days per week without a physician, and expanded it to provide services six days a week with a full-time physician, a full-time nurse practitioner, and a part-time physician.[111] The tribe also successfully took over the CHS program with huge deficits. Prior to the takeover, the CHS program severely restricted its services to "life and limb emergency care." Since the tribal takeover, the CHS program has become an integrated system that carries over funding each year.[112] The tribe is now able to provide a wide variety of services, including elective procedures.[113]

The success of tribally operated health programs also has been documented in a report by the National Indian Health Board (NIHB). According to the 1998 report, *Tribal Perspectives on Indian Self-Determination and Self-Governance in Health Care Management*, tribes that have taken over their health programs under either contracting or compacting agreements have reported improvement in the quality of care.[114] This study confirms that tribes with tribally operated health programs have improved the quality, quantity, and accessibility of services.

The NIHB report found that with self-governance agreements tribes have expanded programs.[115] When IHS direct programs and tribally operated programs are compared, the contracting and compacting tribes had 50 percent more community-based programs; all had at least one new clinical services program; 34 percent had more auxiliary services; and all had at least one new prevention program, with 68 percent having more than one additional prevention program.[116]

Similarly, tribally operated programs added more facilities than IHS direct programs. For those tribes that contract and compact, the study found that 49 new facilities were added and 12

[107] Alan Burgess, tribal health administrator/hospital chief executive officer, Shoshone-Paiute Tribes, e-mail response to USCCR questions, May 1, 2004.

[108] Ibid.

[109] Ibid.

[110] Bill Elliott, health director, Fallon Paiute Shoshone Tribe, e-mail response to USCCR questions, May 14, 2004.

[111] Ibid.

[112] Ibid.

[113] Ibid.

[114] *See generally* NIHB, *Tribal Perspectives*.

[115] NIHB, *Tribal Perspectives*, vol. 2, p. 76.

[116] Ibid., vol. 1, pp. 4–5.

facilities were closed, for a net gain of 37 facilities.[117] The IHS direct service tribes, conversely, added nine new facilities but closed eight, for a net gain of one.[118]

Overall, tribes found success in operating their health programs under the self-governance agreements. One major contributor to this success is the tribe's ability to utilize other incomes and resources to supplement IHS funding.[119] The NIHB study found that the tribes are more likely to use income from economic enterprises to support their health care services and to build new facilities when they operate their own health care programs under contract or compact.[120]

Tribal self-governance has also brought improvements in the quality of care. Most tribal leaders and health directors surveyed by the NIHB indicated that the quality of care has improved through tribal compacts and contracts.[121] The quality of care is measured by waiting times, types of services, number of people served, and overall health care system.[122] More specifically, 57 percent of tribal leaders and 84 percent of tribal health directors participating in the survey indicated that the quality of care had gotten "better" over the past three to four years.[123] Moreover, tribal leaders and health directors from compacting tribes more commonly responded that the quality of care is continuing to get "better."[124] Overall, the NIHB study found tribes that choose to operate their own health programs are better able to add services and improve care.[125]

While tribal operation of health programs has its advantages, potential drawbacks exist. The most significant is the inability to take advantage of "economy of scale," or the fall in average costs resulting from an increase in the scale of production.[126] Economies of scale in health care delivery reduce costs by taking advantage of increased purchasing power in the same manner that large corporate retail stores provide reduced prices to consumers of retail goods.

A second drawback stems from the lack of data coordination and reporting that occurs when tribes act independently of IHS. As a result of tribal autonomy, not all tribes contribute health data to IHS, affecting the availability and accuracy of data on overall Native American health status as well as program administration and funding. Dave Baldridge, formerly with the National Indian Council on Aging, is especially critical of the impact these data problems have on the ability to address health concerns on a national level.[127] In the context of reporting data on

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[117] Ibid., p. 5.

[118] Ibid.

[119] Ibid., p. 6.

[120] Ibid.

[121] Ibid., p. 7.

[122] Ibid., p. 8.

[123] Ibid., p. 7.

[124] Ibid.

[125] Ibid.

[126] Pfefferbaum, *Providing for the Health Care Needs of Native Americans*, pp. 211, 237. *See also* Collins English Dictionary, "economy of scale," <http://www.wordreference.com/english/definition.asp?en=economy+of+scale> (last accessed Dec. 17, 2003).

[127] Baldridge Testimony, Briefing Transcript.

behavioral health, he sees the potential for "500 tribes operating in 500 different directions."[128] If health data are not collected and reported to a central entity, he fears that trends in disease incidence, prevention, and treatment, and other health-related information, will be underreported and could, in the long term, undermine progress in eliminating Native American health disparities.

Third, small tribes often lack the resources and expertise to take over their own health programs. While self-determination contracts and self-governance compacts have allowed large tribes to improve health care services, not all small tribes have been able to take advantage of these programs. Even for the tribes that have taken over their health programs, small tribal services generally lack the technology and the knowledge gained in a larger health care system.[129] As a result, tribal programs are not able to offer more complicated health services and these services are often contracted out to non-IHS facilities under the CHS program. To the extent that tribal programs are under the same financial constraints as direct delivery systems, they face similar obstacles in providing access to quality care. Because tribal programs also rely on the CHS program to provide specialty care and other services not available at tribal facilities, they also face the same formidable obstacles associated with the CHS program, as discussed in the next section.

Contract Health Services Program

Through its Contract Health Services (CHS) program, IHS purchases primary and specialty health care services for eligible Native Americans when services are not available through IHS direct or tribal services.[130] More specifically, IHS may purchase medical care and services from contract health facilities in "situations where: (1) no IHS direct care facility exists; (2) the direct care element is incapable of providing required emergency and/or specialty care; (3) the direct care element has an overflow of medical care workload; and (4) supplementation of alternate resources (i.e., Medicare, private insurance) is required to provide comprehensive care to eligible Indian people."[131] Approximately 18.5 percent of the IHS clinical services budget is appropriated for CHS.[132] IHS administers 48 percent and the tribes manage 52 percent of the CHS programs.[133]

To be eligible for contract health services, an individual must live on a reservation located within a Contract Health Service Delivery Area (CHSDA), or reside within a CHSDA and either be a member of the tribe located on that reservation or maintain close economic and social ties with that tribe.[134]

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[128] Dave Baldridge, telephone interview, Nov. 4, 2003.

[129] Ibid.

[130] This includes patients of IHS and tribally operated facilities. *See* Indian Health Service, "Glossary," <http://www.ihs.gov/PublicInfo/PublicAffairs/Welcome_Info/ThisGlossary.asp> (last accessed Dec. 18, 2003).

[131] IHS, Interrogatory Response 5.

[132] IHS, Interrogatory Response 2.

[133] Ibid.

[134] U.S. Department of Health and Human Services, Indian Health Service, "IHS Manual: Contract Health Services," p. 12, <http://www.ihs.gov/PublicInfo/Publications/IHSManual/Part2/pt2chapt3/pageone.htm> (last accessed June 21, 2004) (hereafter cited IHS, "Contract Health Services Manual").

Contract Health Service Delivery Areas are statutorily established; they may be redesignated by Congress or the Secretary of HHS.[135] The Secretary's decision to redesignate a delivery area may be initiated by a redesignation request from affected tribal group(s), or from IHS after participation with the affected tribal group(s),[136] and is taken after consultation with the tribal governing body of those reservations included in the CHSDA.[137]

Because the Contract Health Services program requires that a patient live in the CHSDA identified for his or her tribe, accessibility to IHS contract health care services is effectively denied when individuals move from their home reservation to urban or rural locations, outside the designated CHSDAs.[138] This creates access issues for Native Americans who live in urban areas.

According to IHS regulations, IHS is the payor of last resort. This means that when a Native American who receives CHS services is eligible for alternate resources such as Medicaid or Medicare, the patient must exhaust all alternate resources before IHS is required to pay. In addition, if a Native American is eligible but does not have alternate resources, IHS assists the patient in applying for alternate resources.[139]

In addition, access to CHS is determined by the availability of funds and, therefore, services under the CHS program are provided only to the extent that funding is available.[140] IHS has the authority under its regulations to establish priorities based on medical needs when CHS funds are insufficient to provide for necessary health services.[141] Accordingly, IHS has established medical priorities for CHS.[142] Tribal programs are also required to follow IHS regulations and use the IHS Medical Priorities as guidelines for setting their medical priorities.[143]

There are five levels of medical priority. Priority I: immediate threat to life, limb or senses (emergent/acutely urgent care services); Priority II: urgent care (primary and secondary care services); Priority III: preventive care; Priority IV: chronic tertiary and extended care services; and Priority V: excluded services.[144] These IHS medical priority levels are reviewed annually.[145] Ultimately, the availability of funds determines the medical care that can be provided. Because of insufficient funds, most areas can only pay for Priority I care.[146] Following the IHS Medical Priority guidelines, each area office develops its own Area Medical Priorities

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[135] 42 C.F.R. § 136.23 (2004); IHS, "Contract Health Services Manual," p. 12.

[136] 42 C.F.R. § 136.22 (2004); IHS, "Contract Health Services Manual," p. 9.

[137] IHS, "Contract Health Services Manual," p. 10.

[138] Indian Health Service, "Health Care Away From Home Reservation," <http://www.ihs.gov/GeneralWeb/HelpCenter/CustomerServices/CHSDA.asp> (June 21, 2004).

[139] 42 C.F.R. § 136.23(e) (2004); *see also* IHS, "Contract Health Services Manual," p. 15.

[140] IHS, "Contract Health Services Manual," pp. 10–11.

[141] Ibid., p. 15.

[142] Ibid.

[143] Ibid.

[144] IHS, Interrogatory Response 5.

[145] IHS, "Contract Health Services Manual."

[146] IHS, Interrogatory Response 5.

that integrate the annual spending plan.[147] Every time an area office updates its Medical Priorities list, a copy is submitted to the headquarters, CHS branch. Using its system of medical priority levels, each area office determines the authorization for CHS.[148] Once a request for CHS is submitted to the Area CHS reviewing committee, such as a CHS Resource Management Committee or Managed Care Committee, the strict regulations guiding the authorization of CHS are applied to determine whether to grant, defer, or deny the CHS referral request.[149] These review committees consist of both clinical and administrative staff of the facility.[150]

Under the regulations, no authorization for CHS and no payment will be made for medical care from non-IHS providers unless: (1) the patient meets the IHS eligibility requirement for residence, (2) the health care provider first notifies the IHS ordering official of the need for service and provides appropriate information to determine the relative medical priority for the requested service, and (3) the provider receives prior authorization.[151] According to IHS, the justification for denial of payment for CHS may include the following: an IHS facility was available, an alternate resource was available, the patient has lived out of his CHSDA for over 180 days, notification was not received within 72 hours, insufficient information was provided, and/or no appeal was made within 30 days.[152]

Following a denial of CHS, a patient may appeal that decision under the IHS formal appeals mechanism. The IHS appeals process involves three levels: the service unit, the area director, and the director of IHS.[153] Tribes that contract or compact their health services establish their own procedures and operate under their own appeals process.[154] For tribal systems, the chief executive officer or the director of the facility becomes the final appeals authority of all CHS appeals.[155] The composition of the group that adjudicates the formal appeals is determined at the local level.[156] Generally, members are chosen based on their expertise and are often physicians, registered nurses, physician assistants, or health care administrators.[157] While tribally operated systems have some flexibility in the composition and operation of their appeals committee, like the IHS direct systems, they are expected to operate in the same manner and in accordance with federal regulations.[158] This appeals process, a quasi-legal process, can involve individual patients submitting documentation to support their appeal, or IHS staff contacting tribal representatives or individual Native Americans to verify information provided.[159]

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[147] IHS, "Contract Health Services Manual"; IHS, Interrogatory Response 5.

[148] IHS, "Contract Health Services Manual."

[149] Ibid. IHS, Interrogatory Response 5.

[150] IHS, Interrogatory Response 5.

[151] IHS, "Contract Health Services Manual," p. 20; IHS, Interrogatory Response 3.

[152] IHS, Interrogatory Response 3.

[153] Ibid.

[154] Ibid.

[155] Walker interview; Burgess interview.

[156] IHS, Interrogatory Response 3.

[157] Ibid.

[158] Ibid.

[159] Ibid.

Despite the extensive formal appeals process to review denied CHS requests, a large portion of the requests go unfulfilled. While IHS is willing to review any denied CHS request, it acknowledges that, because of insufficient funds, it is forced to limit the types of services provided to Native Americans.[160] Rationing is an unfortunate reality for IHS.[161] While IHS no longer requires area office staff to provide information on the number of appeals and types of services that have been approved for payment,[162] the sheer number of denied CHS cases indicates the impact of rationing, an impediment to access.

As a further impediment to accessing quality health care, IHS requires that other non-IHS sources be exhausted for payment before contract services are sought.[163] As explained above, IHS is the payor of last resort.[164] This means that while the patient may still receive a referral, instead of IHS paying the bill, the referral lists the alternate health care provider as the payor, subject to any applicable restrictions.[165] If the alternate provider requires any deductible or co-payment, IHS may pay, if funding is available.[166]

In recent years, the denial of CHS payments has increased more than 75 percent from 1998.[167] In FY 2000, of the 680,350 requests for CHS, IHS authorized 329,236 and denied 124,576 cases. For FY 2001, of the 663,962 requests, 318,745 cases were authorized and 131,204 were denied. Similarly, in FY 2002, of the 638,765 requests for CHS, 324,191 were authorized and 134,179 cases were denied. In FY 2003, of the 571,926 requests, 318,449 cases were authorized and 144,392 were denied.[168] Reviewing the information IHS provided, there is a discrepancy in the total number of CHS requests and the total number of authorized and denied cases. The IHS did not provide an explanation for this discrepancy. The discrepancy, however, appears to indicate that there were a large number of de facto denials of CHS requests resulting from IHS inaction. Accordingly, the total number of denied CHS requests would be greater, indicating an overall CHS denial rate that may be worse.

The denial rate has reached the point that the existence of a "loss of life or limb" rule is commonly recognized.[169] Ed Fox, executive director of the Northwest Portland Area Indian Health Board, observed that by August of each year, with several weeks remaining in the fiscal

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[160] IHS, Interrogatory Response 5.

[161] Ibid.

[162] Ibid.

[163] Holly T. Kuschell-Haworth, *Jumping Through Hoops: Traditional Healers and the Indian Health Care Improvement Act*, 2 DEPAUL J. HEALTH CARE L. 843, 844 (1999) (hereafter cited as Kuschell-Haworth, *Traditional Healers and the Indian Health Care Improvement Act*).

[164] IHS, Interrogatory Response 3.

[165] Ibid.

[166] Ibid.

[167] ITU Budget Workgroup, "FY 2003 Needs Based Budget Presentation," <http://www.npaihb.org/index.html> (last accessed Aug. 19, 2003).

[168] IHS, Interrogatory Response 2.

[169] ITU Budget Workgroup, "FY 2003 Needs Based Budget Presentation," <http://www.npaihb.org/index.html> (last accessed Aug. 19, 2003). *See also* Jack Testimony, Briefing Transcript, p. 26.

year, most facilities either defer or deny gallbladder surgeries and eyeglass prescriptions, as well as other services of equivalent urgency.[170]

As an illustration of the degree to which CHS limits care, IHS officials identified one facility where only 14 of 45 cases needing referral for necessary services were even forwarded for CHS review.[171] Even fewer of those reviewed actually received contracted care.[172] This problem is not isolated to a single facility. The Cherokee Nation Health Services, for example, denied 4,300 CHS referrals in FY 2003. These reported denials underestimate the real number of necessary services that are not provided under CHS since providers cease writing referrals for CHS when they know that service will be denied.[173] The unfortunate reality is that the severe underfunding of CHS programs causes IHS to ration health services. Cherokee Nation Health Services reports that it is unable to fund many requests for cancer treatment and diagnostic services. Officials there explained that this rationing of care has a direct impact on the overall health status of the Cherokee Nation.[174] The most disturbing of their claims is that denied or delayed medical treatments correlate directly to increased mortality rates.[175]

Further, due to restricted funding, those patients awaiting more routine care experience lengthy delays and unnecessary complications.[176] For example, Cherokee Nation states that a child experiencing recurring ear infections would not be referred to an ear, nose, and throat specialist for treatment until the child shows signs of hearing loss.[177]

Dr. Craig Vanderwagen, acting chief medical officer for IHS, acknowledged how rationing health care is not the optimal method of treating patients:

> We don't feel good about the number of patients who need care who are rejected because their problem is not life-threatening. . . . It's rationing. We hold them off until they're sick enough to meet our criteria. That's not a good way to practice medicine. It's not the way providers like to practice. And if I were an Indian tribal leader, I'd be frustrated.[178]

In summary, the rationing of health care leads to the denial or delay of treatment, and compels patients to accept cheaper and less effective treatment interventions or to go without care.[179] While there is insufficient data to assess the actual impact of rationing services on mortality and morbidity rates, denying or delaying treatment as a result of rationing inevitably worsens the overall health status of Native Americans.

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[170] Fox interview.

[171] Vanderwagen interview.

[172] Ibid.

[173] Cherokee Nation Health Services, "Contract Health Services" (information packet from USCCR visit to Cherokee Nation, Mar. 25–26, 2004).

[174] Staff meeting with the Cherokee Nation in Oklahoma, Mar. 25–26, 2004 (hereafter cited as the Cherokee Nation Meeting).

[175] Ibid.

[176] Joe, "The Rationing of Healthcare," pp. 539–42. *See also* Vanderwagen interview.

[177] Cherokee Nation Health Services, "Contract Health Services" (information packet from USCCR visit to Cherokee Nation, Mar. 25–26, 2004).

[178] Vanderwagen interview.

[179] Joe, "Rationing," p. 549.

Although Contract Health Services programs provide health care otherwise unavailable through IHS direct or tribal providers, the limited services and rationing of care erect an insurmountable barrier, ensuring Native Americans will not have full access to adequate health care.

Urban Indian Health Programs

While IHS direct and tribal services provide health care on and near reservations, the Urban Indian Health Programs serve urban Native Americans. According to the 2000 census data, 61 percent of the Native American population live in urban areas. Urban Indian Health Programs are the only IHS facilities available to this majority of the Native American population, short of returning to those on the reservation. In actual terms, Urban Indian Health Programs serve only an estimated 150,000 Native Americans.[180] This represents 6 percent of the total Native American population, though approximately 25 percent live in areas where they could potentially be served by these urban programs.[181] Not all urban Indians live in areas where service is available; a staggering 46 percent of all Native Americans, or more than 1 million, remain with no access to IHS facilities.[182]

These urban Indian programs, which began as not-for-profit clinics and survived on donated equipment, supplies, and volunteer services, became slightly more reliable sources of care with funding through the Indian Health Care Improvement Act (IHCIA).[183] Title V of IHCIA allows for minimal federal funding to sponsor operation of Urban Indian Health Programs.[184] The Title V program seeks to provide outpatient health services for urban Indians.[185] The IHS funds these urban services, whether direct care or referral services, through contracts with nonprofit organizations controlled by urban Indians.[186]

For FY 2004, $31.5 million was requested for the Urban Indian Health Programs, an increase of $245,000 from FY 2003. The $31.5 million amounts to an average of $210 per user.[187] Despite the growing number of Native Americans residing in urban settings, IHS has

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[180] Of these 150,000, approximately 100,000 either do not meet IHS eligibility criteria or reside outside IHS and tribal service areas. U.S. Department of Health and Human Services, Indian Health Service, "Urban Indian Health Programs," <http://www.ihs.gov/NonMedicalPrograms/Urban/ UIHP.asp> (last accessed Mar. 26, 2004); Forquera, *Urban Indian Health*, pp. 9–10. Another 49,000 Native Americans use urban programs in cities located in IHS direct or tribal service delivery areas. Ibid.

[181] Urban Indian Health Institute, "The Health Status of Urban American Indians and Alaska Natives: An Analysis of Select Vital Records and Census Data Sources," Mar. 16, 2004, p. 4.

[182] Ibid. *See also* Northwest Portland Area Indian Health Board, *FY 2004 IHS Budget Analysis and Recommendations* (14th Annual), Mar. 19, 2003, pp. 7, 25 (hereafter cited as Northwest Portland Area Indian Health Board, *FY 2004 IHS Budget Analysis*).

[183] Joe, "The Rationing of Healthcare," p. 535.

[184] Ibid.

[185] Forquera, *Urban Indian Health*, p. 9.

[186] Ibid.

[187] Urban Indian Health Institute, "The Health Status of Urban American Indians and Alaska Natives: An Analysis of Select Vital Records and Census Data Sources," Mar. 16, 2004, p. 4. *See also* Chapter 4 to compare this value with that spent on other Native Americans and the amount spent on others receiving federally funded health care.

allocated only about 1 percent of its annual appropriations for urban programs since 1979.[188] This 1 percent of past appropriations serves about 25 percent of the entire Native American population.

Currently, approximately 34 Urban Indian Health Programs in more than 41 locations are partially supported by IHS.[189] The balance of their funding is obtained through tribal support, public and private grants, and revenues from Medicaid and Medicare payments and private insurance reimbursements.[190] The services provided vary among the 34 programs. Of the 34 programs, 21 are comprehensive clinical programs, six are limited clinical programs, and seven are outreach and referral programs only.[191] The types of services these urban programs provide depend on the availability of non-IHS funding in the region to supplement Title V appropriations.[192] Among the 20 cities with the largest Native American populations, 10 cities have programs that provide medical services, six have programs that mainly offer referral services, and four are without any urban programs.[193] Urban Indians who are on public assistance, unemployed, or employed in jobs without health benefits most often use these facilities.[194]

Unlike IHS and tribal health services that are provided without charge to eligible Native Americans, Urban Indian Health Programs provide services on a sliding fee basis and many of the services are restricted to primary care.[195] The opportunity to use contract health services when primary and specialty care is unavailable is not an option for urban Indians as it is for Indians using IHS direct delivery and tribal programs. As explained in the Contract Health Services section, contract health services are available only to those Native Americans who live within the Contract Health Service Delivery Areas. Tribal members who live off the reservation for over 180 days are not eligible to receive contract health services.[196] Accordingly, urban Indians must pay for themselves when referred for such services as inpatient hospital care, specialty services, and diagnostics.[197]

IHS acknowledges that Native Americans in urban areas face barriers to accessing hospitals, health clinics, and contract health services provided by IHS and tribes.[198] The agency attributes urban Indian access problems to poverty, lack of health insurance, and the dearth of

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[188] Forquera, *Urban Indian Health*, p. 8.

[189] U.S. Department of Health and Human Services, Indian Health Service, "Urban Indian Health Programs," <http://www.ihs.gov/NonMedicalPrograms/Urban/ UIHP.asp> (last accessed Mar. 26, 2004); Forquera, *Urban Indian Health*, pp. 9–10.

[190] Forquera, *Urban Indian Health*, p. 10.

[191] IHS, Interrogatory Response 34.

[192] Forquera, *Urban Indian Health*, p. 12.

[193] These 10 cities that provide medical services are Albuquerque, Chicago, Denver, Oklahoma City, Minneapolis, Portland, San Diego, San Jose, Seattle, and Tulsa; the six cities that provide referral services are Dallas, Fresno, Los Angeles, New York, Phoenix, and Tucson; and the four cities without urban programs are Anchorage, Houston, Mesa, and San Antonio. Forquera, *Urban Indian Health*, p. 12.

[194] Joe, "The Rationing of Healthcare," p. 535.

[195] Forquera, *Urban Indian Health*, p. 12.

[196] 42 C.F.R. § 136.23(c) (2004).

[197] Forquera, *Urban Indian Health*, p. 12.

[198] IHS, Interrogatory Response 33.

culturally sensitive physicians and other health professionals.[199] While as tribal members, Native Americans in urban areas can access tribally operated services, access to that care is further impeded by lack of transportation.[200]

According to Norman Ration, executive director of the National Indian Youth Council, although Native Americans are moving to urban areas in growing numbers, "IHS does not get it when it comes to addressing the health care needs of urban Indians."[201] Kay Culbertson, executive director of the Denver Indian Health and Family Services, also testified that urban Indians have become invisible to federal policies; everything is geared toward tribal members living on the reservations.[202] She added that the health care needs of Native Americans living off reservation are as great or even greater than the needs of Native Americans who live on their homelands—and their needs should be recognized.[203]

Documenting the health disparities of urban Indians and the pressing need for an adequate health care system serving urban Indians, a report released in March 2004 by the Urban Indian Health Institute concluded that Native Americans living in urban areas are at a greater risk of poor health than most Americans.[204] The report found that Native Americans in the 34 urban areas served by IHS-funded Urban Indian Health Organizations have rates 38 percent higher for death due to accident, 126 percent higher for chronic liver disease and cirrhosis, and 54 percent higher for diabetes than general population rates.[205]

Accordingly, while the health disparities among Native Americans in general are great, the disparities are even greater for Native Americans living in urban areas. As IHS admits, it has the responsibility to eliminate barriers, elevate health status, and reduce the health disparities among Native Americans in urban areas.[206] IHS states that it addresses its responsibility by funding, through contracts and grants, 34 urban programs, and 10 alcohol and substance abuse programs.[207] As mentioned, however, IHS funding for its urban programs—which serve 25 percent of the Native American population—makes up a scant 1 percent of total IHS appropriations.

When asked to explain any changes made or proposals to improve health care for the growing urban Indian population, IHS failed to provide examples of significant programmatic improvements. It pointed to improvements in the urban program's data collection system, the establishment of an urban Indian epidemiology center, and more focus on the involvement of urban programs in the agency's consultation efforts.[208]

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[199] Ibid.

[200] Ibid.

[201] Ration Testimony, Briefing Transcript, p. 78.

[202] Culbertson Testimony, Briefing Transcript, p. 268.

[203] Ibid., p. 276.

[204] Urban Indian Health Institute, *The Health Status of Urban American Indians and Alaska Natives*, Mar. 16, 2004, p. 31.

[205] Ibid., p. v.

[206] IHS, Interrogatory Response 33.

[207] Ibid.

[208] IHS, Interrogatory Response 34.

As discussed in Chapter 4, the underfunding of urban Indian programs is a crisis. Compounding the problem may be a lack of representation for urban Indians. Norman Ration of the National Indian Youth Council said that urban Indians were disproportionately represented in discussions before Congress and IHS.[209] Mr. Ration explained that, among other problems, the inability to voice urban Indian concerns has resulted in funding mechanisms that allow funds designated for urban Indians to be spent by tribal health programs.[210] He clarified that as tribes compact services that were provided by hospitals, tribes take the funds intended for their tribal members and use the funds for services provided on reservation.[211] According to IHS, however, the urban program is a budget line item in the IHS budget.[212] Urban projects are funded separately from the IHS program for Native Americans on or near reservations.[213] Mr. Ration, nonetheless, is concerned that urban Indians do not have a voice to express their concerns when it comes to funding distribution.[214]

Clearly, urban Native Americans face greater challenges in accessing health care services, and the resulting reality is disproportionate health status and outcomes. As more Native Americans move to urban areas, health care needs will only increase. Unfortunately, funds appropriated for urban Indian health care are only 1 percent of total IHS appropriations. Further, IHS has not implemented any programmatic changes to address the growing urban population. Any initiatives to eliminate health disparities for Native Americans must include measures to address the specific health needs of Native Americans living in urban areas.

Structural Barriers to the Use of IHS Facilities

While the three service delivery programs within IHS have varying advantages and disadvantages, the overarching problem with the IHS system is limited access. This section explores some of the factors that limit access to IHS facilities. The manner in which IHS manages, operates, and administers its health system can create barriers for Native Americans both in terms of physical access and in terms of the quality of services received. Accordingly, this section reviews the IHS management, operation, and administration of its delivery system, and assesses the quality of care issues created by the system itself.

Remoteness of IHS Facilities

For the more than 538,000 Native Americans living on reservations or other trust lands where the climate is inhospitable, the roads are often impassable,[215] and where transportation is

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[209] Ration Testimony, Briefing Transcript, p. 78. *See also* a more detailed discussion including recommendations in Chapter 4.

[210] Ibid.

[211] Ration interview, Apr. 15, 2004.

[212] IHS, Interrogatory Response 21.

[213] Ibid.

[214] Ration interview, Apr. 15, 2004.

[215] *Anchorage Daily News*, "Native Americans in the Census," Nov. 1, 2002, <http://www.adn.com/alaska/v-printer/story/2059310p-2157469c.html> (last accessed July 15, 2003); Restructuring Initiative Workgroup, *Transitions 2002: A 5-Year Initiative to Restructure Indian Health, Final Report to the Indian Health Service*, October 2002 (hereafter cited as Restructuring Initiative Workgroup, *Transitions 2002*).

scarce, health care facilities are far from accessible. Anslem Roanhorse, director of the Division of Health for the Navajo Nation, testified that on the Navajo reservation 78 percent of the public roads are unpaved and 60 percent of the homes lack telephone service.[216] Even worse, for those who can get to the facilities, the equipment, medicine, and services are often not available for necessary treatment. Traveling to more distant facilities and delaying treatment are the only options. For example, in Eagle Butte, South Dakota, the Cheyenne River Sioux Tribe does not have an obstetrics unit in its hospital and is worried that the new proposed hospital will not have one. "Obstetrics services for the tribe's approximately 210 births a year are contracted out, 'and last year there were five births in the ambulance on the way to Pierre,' 90 miles away," according to tribal leaders.[217] IHS has announced that the new facility will have an obstetrics unit, however, there is concern that there will be insufficient funding to hire an obstetrician.[218] For the Kalispel Tribe in Usk, Washington, the problem extends beyond specialty services. They have no on-site primary care at this time; tribal members must travel 75 miles to receive care at the Wellpinit Service Unit IHS clinic or use an IHS contract facility, if available.[219] Geographical access problems are not limited to remote, rural areas. For the 25,000 urban Indians living in Denver, Colorado, the closest IHS hospitals are in Albuquerque, New Mexico (450 miles away) and Rapid City, South Dakota (400 miles away).[220]

The geographical access problem is not a new problem facing IHS. It has long been recognized that geographic location and the resulting transportation problems hamper IHS efforts to provide health services.[221] In 1976, by passing the Indian Health Care Improvement Act to raise the health status of Native Americans, Congress acknowledged the grave health disparities Native Americans were facing.[222] Among other access problems, Congress explained that many Native American patients were "hitchhiking" or relying on costly rides from neighbors to get to IHS facilities.[223] This situation, unfortunately, has not changed today. Many Native Americans continue to depend on others traveling to IHS facilities.[224] Because of unpredictable travel arrangements, they are unable to plan ahead and make appointments at the IHS facilities; thus, many show up without appointments, leading to long wait times at the facilities. The problem is magnified as many facilities are unable to accommodate walk-in patients and limit their services to appointment-only services.[225]

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[216] Roanhorse Testimony, Briefing Transcript, p. 139.

[217] Peter Harriman, "Indian Health Worries Shared," *Argus Leader*, Aug. 25, 2003, p. 1A.

[218] Cheyenne River Sioux Tribe, "Press Release: A Birthing Unit Will become a Reality for the New Hospital Planned on the Cheyenne River Sioux Reservation," <http://www.sioux.org/archive_birth_unit.html>, (last accessed August 2, 2004).

[219] American Indian Health Commission of Washington State, "2003 American Indian Health Care Delivery Plan," July 2003, p. 103, <http://www.aihc-wa.org/Issues/AIHCDP.htm> (last accessed Aug. 28, 2003).

[220] *The Reauthorization of the Indian Health Care Improvement Act: Hearing Before the Senate Indian Affairs Comm.*, 107th Cong. (2001) (statement of Kay Culbertson, executive director, Denver Indian Health and Family Services).

[221] S. Rep. No. 94-1194, at 73 (1976), *reprinted in* 1976 U.S.C.C.A.N. 2711.

[222] *Id.* at 2652.

[223] *Id.* at 2710–11.

[224] Roanhorse interview.

[225] Visit with the Cherokee Nation. According to the IHS officials at the service unit in the Cherokee Nation, its services are limited to patients with appointments. Ibid.

At IHS facilities serving the Cherokee Nation, certain diagnostic tests are provided on specified dates each month. If a patient is unable to get to the facility during the times these services are provided, the patient must go without the service until the test is offered again.[226] The providers and administrators at IHS facilities in Cherokee Nation all agreed that delayed services result in adverse health outcomes.[227] A presumably treatable condition left unaddressed often leads to more serious conditions or unnecessary complications.

While insufficient funding can make providing transportation or locating facilities closer to Native Americans difficult, IHS nonetheless has the responsibility for ensuring its facilities and services are accessible. The IHS has developed the Health System Planning software and is developing the proposed Small Ambulatory Health Care Facility (SAHCF) Criteria as the main guide for planning IHS facilities.[228] In addition, the 12 IHS areas are developing Area-Wide Health Services and Facilities Master Plans (AHSFMPs) to better plan the location of new health facilities.[229] The IHS is optimistic that the SAHCF Criteria will provide consistent and appropriate health care guidance to remote Native American communities. The AHSFMPs will establish a conceptual direction for new health care services. The IHS did not provide details on how the SAHCF Criteria and AHSFMPs will ensure that IHS facilities comprehensively address the community health needs.

Clearly, because tribes best understand their own community health needs, tribal representatives must play a crucial role in determining the location of IHS facilities and the types of services to be provided. The IHS agrees that tribes should fully participate in the development of data and provide input into health care delivery program choices in their service areas.[230] However, it is unclear whether tribes have meaningful or effective input into the overall IHS health care delivery program decisions.

Under the Indian Self-Determination and Education Assistance Act and the Indian Health Care Improvement Act, IHS is required to consult with tribes and to ensure effective and meaningful participation of Native Americans in the planning, conduct, and administration of programs and services that affect Native Americans. In 1997, IHS promulgated the first comprehensive Tribal Consultation and Participation Policy in the federal government.[231] Under the policy, tribal consultations take place on three management levels: headquarters, area offices, and service units.[232] At each level, managers are required to establish advisory committees, which provide advice and consultation to the IHS managers.[233] IHS managers are encouraged to establish additional forums for tribal consultation and participation.[234] The implementation of

[226] Ibid.

[227] Ibid.

[228] IHS, Interrogatory Response 35.

[229] Ibid.

[230] IHS, Interrogatory Response 36.

[231] U.S. Department of Health and Human Services, Indian Health Service, "Consultation and Participation by Tribes," <http://info.ihs.gov/TreatiesLaws/Treaties4.pdf> (last accessed Apr. 7, 2004).

[232] U.S. Department of Health and Human Services, Indian Health Service, *Tribal Consultation and Participation Policy, Indian Health Service Circular No. 97-07*.

[233] Ibid.

[234] IHS, Interrogatory Response 51; U.S. Department of Health and Human Services, Indian Health Service, *Tribal Consultation and Participation Policy, Indian Health Service Circular No. 97-07*.

this policy is a critical performance element for the annual performance standards of principal managers at IHS.[235]

While the tribal consultation policy calls for effective and meaningful participation of tribes and individual Native Americans, the policy lacks a measure to assess the effectiveness and meaningfulness of the tribal consultation and participation. Tribes vary in size, resources, health needs, and expertise in health policies. While larger tribes with more resources hire representatives and experts to study the impact of IHS policy on their tribes and to best present their views, some of the small tribes lack the resources and expertise necessary to represent their issues and concerns.[236] One tribal representative stated that while IHS frequently "invites" tribes to consultative meetings and sessions, unless travel is fully funded, many small tribes and some large ones cannot afford to send representatives.[237] Another tribal representative expressed the frustration that tribal consultation is often "one-sided" and structured in a "non-Native" way, without respect to the Native culture.[238] According to one tribal representative, the sheer number of tribes nationally can create logistical difficulty in tribal consultation.[239] Another tribal representative added that while IHS is better at considering tribal views than other federal agencies, IHS tribal consultation does not equate to responsiveness.[240] He stated that because of distance and revenue, small tribes have a disadvantage when it comes to consultation.[241]

Any consultation and participation policy aimed at increasing effective and meaningful participation must also include a mechanism to provide the necessary assistance. Existing IHS policy does not have a mechanism to provide this type of assistance. Absent such a mechanism, it is difficult to conclude that tribes have meaningful and effective participation in the decision-making process at IHS. Thus, many tribes and their tribal members continue to face geographical challenges in accessing IHS facilities.

Telemedicine

Where IHS locates its facilities ultimately affects how accessible its services are to Native Americans. As stated, IHS is developing new criteria and guidelines to determine its plans for IHS facilities and soliciting input to ensure that the placement of facilities and the types of services to be provided are determined based on community needs. One notable step IHS has taken to address the geographical barrier between remote communities and health care providers is telemedicine.[242] IHS is applying technology to bring primary care and specialty medicine to

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[235] U.S. Department of Health and Human Services, Indian Health Service, *Tribal Consultation and Participation Policy, Indian Health Service Circular No. 97-07*.

[236] Bird interview.

[237] Burgess e-mail response.

[238] Rundlet e-mail response.

[239] Newcombe e-mail response.

[240] Elliot e-mail response.

[241] Ibid.

[242] U.S. Department of Health and Human Services, Indian Health Service, "Telemedicine and Telehealth Projects," <http://www.ihs.gov/nonmedicalprograms/dfee/telmed/default.cfm?content=coverpage.html> (last accessed Apr. 22, 2004).

remote locations.[243] Telemedicine "refers to the use of electronic communication and information technologies to provide or support a diverse group of health-related activities that may include health professionals' education, community health education, public health research, and the administration of health services."[244] There are about 40 telemedicine programs and partnerships within IHS that are delivering care to smaller, more isolated communities.[245]

For example, clinical engineers are equipping small remote villages in Alaska with telemedicine systems to transmit digital images of patients' eardrums, skin conditions, and even tonsils to distant health care providers.[246] Through telemedicine, small rural communities can communicate during emergencies with social workers via video conferencing when transportation is difficult or impossible.[247] Telemedicine allows pre- and post-operation services to be provided at the local facility and eliminates trips to regional medical centers.[248] The local on-site primary care provider can receive quick consults from regional medical centers, which results in a faster treatment time.[249] It also provides access to continuing medical and community education.[250] Telemedicine has the potential to eliminate some of the geographical access issues for Native Americans in rural communities.[251]

Although promising, the IHS telemedicine program is not yet widely used. According to a report prepared by the American Indian Information Network for IHS, which identified and inventoried telemedicine use within IHS and tribal clinics, there are barriers to telemedicine access.[252] The report found that access to affordable telecommunications is the major barrier to implementing telemedicine projects in rural America and especially in Indian Country.[253] Many projects, it found, had difficulty obtaining services. For example, it took the University of Arizona more than a year to negotiate with telecommunications companies to establish service to the IHS Tuba City Indian Medical Center and the Navajo National Sage Memorial Hospital.[254]

The report also noted a cultural barrier associated with distance education and medicine, where the providers themselves were unable or hesitant to incorporate technology into service delivery.[255] While IHS/tribal clinics recognize the immediate value of telemedicine for cutting

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[243] Ibid.

[244] U.S. Department of Health and Human Services, Indian Health Service, Department of Environmental Health & Engineering, "Telemedicine & Telehealth Projects Serving Indian Health Service & Tribes," October 2000, p. 7.

[245] U.S. Department of Health and Human Services, Indian Health Service, "Telemedicine and Telehealth Projects," <http://www.ihs.gov/nonmedicalprograms/dfee/telmed/default.cfm?content=coverpage.html> (last accessed Apr. 22, 2004).

[246] Ibid.

[247] Ibid.

[248] Ibid.

[249] Ibid.

[250] Ibid.

[251] Ibid.

[252] U.S. Department of Health and Human Services, Indian Health Service, Department of Environmental Health & Engineering, "Telemedicine & Telehealth Projects Serving Indian Health Service & Tribes," October 2000, p. 24.

[253] Ibid.

[254] Ibid.

[255] Ibid., p. 25.

travel costs for training or administrative meetings, telemedicine is viewed as a luxury and clinics cited structural reasons why use was low.[256] Two top reasons cited for infrequent use of telemedicine are high patient loads and employee turnover that keep staff from learning and maintaining skills on equipment use.[257]

Because of these barriers, the benefits of telemedicine have not been fully recognized. With the proper use of telemedicine, some of the geographical access barriers may be reduced or eliminated. The unfortunate reality, however, is that telemedicine is not widely used and has not resolved the geographical barriers challenging access to health care for Native Americans in rural communities.

Aging and Outdated Facilities

IHS also faces the challenge of dealing with aging facilities. The average age of current IHS facilities is 32 years, compared with nine years for private sector facilities,[258] indicating that a massive modernization program is urgently needed.[259] New and properly designed facilities are needed to provide efficient space in which to provide services.[260] Older IHS facilities tend to be "inefficient and haphazard in their arrangement of space,"[261] and some are beyond capacity. The oldest facilities may not be in compliance with Occupational Safety and Health Administration and Americans with Disabilities Act standards.[262]

Claremore Indian Hospital, in Claremore, Oklahoma, illustrates the problems older facilities face. Though built in 1977 for an anticipated patient population of 36,000, as of 2001, the hospital had more than 136,484 registered patients.[263] In addition, the hospital was constructed as a 60-bed inpatient facility with 14 examination rooms.[264] As it shifted services from inpatient care to outpatient care following the modern health care trend, the layout of the facility became inadequate. Lack of space to serve patients caused crowded waiting rooms, low productivity by providers, and ultimately patient dissatisfaction.[265]

Because of the overwhelming financial constraints discussed in greater detail in Chapter 4, IHS has been unable to renovate its older facilities. An IHS survey in November 2002

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[256] Ibid., p. 26.

[257] Ibid., p. 24.

[258] *See* U.S. Department of Health and Human Services, Indian Health Service, "Strategic Plan: Improving the Health of American Indian and Alaska Native People Through Collaboration and Innovation," p. 5, and Perez Testimony, Briefing Transcript, p. 16.

[259] Restructuring Initiative Workgroup, *Transitions 2002*.

[260] U.S. Department of Health and Human Services, Indian Health Service, Office of Public Health, Division of Facilities and Environmental Engineering Health Care Facilities Engineering, *Millennium Report and Accomplishments Since 1954*, January 2000, p. 32.

[261] Ibid.

[262] Roanhorse interview.

[263] Jim Cussen, chief executive officer, Claremore Indian Hospital, telephone interview, May 27, 2004.

[264] Ibid.

[265] Ibid. U.S. Department of Health and Human Services, Indian Health Service, Office of Public Health, Division of Facilities and Environmental Engineering Health Care Facilities Engineering, *Millennium Report and Accomplishments Since 1954*, January 2000, p. 32.

estimated a backlog of $506 million in needed facilities repairs alone.[266] As IHS has acknowledged, its aging facilities pose a serious threat to providing quality services to Native Americans.[267] The IHS decision not to devote resources to modernize aging facilities works as a barrier for Native Americans in accessing quality services. Furthermore, without the appropriations for facility renovations, IHS hospitals at local levels sometimes rely on their own third-party collections to conduct badly needed reconfiguration and renovations, consuming funds that could go toward patient care.[268] Accordingly, proper resources must be devoted to renovating and reconfiguring some of the older IHS facilities, without taking resources away from patient care.

Extended Wait Times at IHS Facilities

One of the problems of aging facilities, as explained above, is that an outdated layout leads to an insufficient use of space, which can lead to crowded waiting areas and reduced staff and provider productivity.[269] Lower productivity and the inefficient use of space can cause long delays, one of the most frequent complaints among Native American patients at IHS facilities.

Long wait times at IHS facilities have been widely acknowledged as a serious problem facing Native Americans: for example, Senator Tom Daschle referenced long wait times in his Floor Statement on Indian Health Amendment to the FY 2004 Budget Resolution.[270] IHS hospital administrators also admit that poorly designed configurations and a lack of space cause long delays in receiving services.[271] At hearings held by the Cheyenne River Sioux Tribal Council, many Native Americans came forward complaining that they are often required to wait long periods before being seen by their providers. According to one speaker, Native American patients typically "wait to see the doctor first. They wait to get their vitals taken. Then they wait to see the doctor. Then they wait to get the prescriptions."[272] The same speaker, a Native American woman, said she must rely on the IHS Community Health Representative program to transport her to the clinic, and said she would have to get to the clinic in the morning even though her appointment was in the afternoon. Once at the clinic, she would wait up to three hours after her appointment just to get medication.[273] Another Native American explained that because the IHS facilities are "behind times," patients have to wait to see their providers.[274]

Whether the long wait times are self-created by patients walking into the facility without appointments, by insufficient use of space and the resulting low productivity of providers and staff, or by inefficient management and operation of the facilities, it is well established that IHS

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[266] Results from Backlog of Essential Maintenance and Repair (Survey) as reported in Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," p. 30.

[267] Ibid.

[268] Cussen interview.

[269] Ibid.

[270] Senator Tom Daschle, "Floor Statement on Indian Health Amendment to the FY 2004 Budget Resolution," Mar. 24, 2003, <http://daschle.senate.gov/pressroom/speeches/03/03/20030324.html> (last accessed Feb. 23, 2004).

[271] Cussen interview.

[272] Barbara Iron Wing, LaPlant Hearing, Mar. 15, 2002, p. 87.

[273] Ibid.

[274] David Bald Eagle, Bridger Hearing, Apr. 11, 2002, pp. 19–20.

needs to take measures to address this problem. The Commission could not find, and the IHS did not provide, any information indicating that IHS had taken steps to reduce the long wait times that are now common at its facilities.

Quality of Care Issues

In addition to physical access, access to care encompasses providing and receiving quality care. Undoubtedly, funding for health care affects the quality of health services, and increases in funding would significantly and immediately improve the quality of health services. Nevertheless, several other factors can affect a facility's ability to provide quality health services, such as maintaining qualified staff capable of accurately diagnosing diseases, as well as treating patients in a culturally appropriate and acceptable manner. Chapter 2 addressed the issue of language barriers and culturally competent health care services. This section discusses two other "quality" problems faced by IHS: the ability to recruit and retain qualified providers and the misdiagnosis or late diagnosis of diseases.

Ability to Recruit and Retain Health Providers

The ability to recruit and retain competent health care providers has a direct bearing on the quality of care at a health facility. In some cases, poor quality creates high turnover rates. Not surprisingly, highly trained medical personnel get frustrated at the inability to provide care at the level they were trained to provide. In addition, overworked staffs quickly develop burnout.[275] In other situations, high turnover rates result in a poor quality of service. High turnover rates leave gaps where facilities are undermanned and disrupt continuity of care.

Historically, IHS has experienced shortages in doctors, dentists, pharmacists, and nurses.[276] The IHS director testified that vacancy rates range anywhere from 8 to 23 percent.[277] In 2001, his staff reported that the physician vacancy rate for IHS facilities was 10 percent, and the average length of service for IHS physicians was 8.1 years.[278] Consequently, Dr. Grim reported that the agency must hire almost 1,200 doctors in order to fill 900 vacant physician positions each year.[279] IHS has had difficulty achieving this goal, which it primarily attributes to the remoteness of some sites.[280] The vacancy rate for other health care professionals also causes concern. For example, in 2001, IHS experienced a vacancy rate of 22 percent for dentists and 14 percent for optometrists.[281] IHS has also recognized that it is experiencing a shortage of

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[275] Open Session before the U.S. Commission on Civil Rights, Gallup Medical Facility, Gallup, NM, Oct. 16, 2003. Remarks of Dr. Jana Gunnell, New Mexico Department of Public Health.

[276] Restructuring Initiative Workgroup, *Transitions 2002.*

[277] Grim Testimony, Briefing Transcript, p. 61.

[278] U.S. Department of Health and Human Services, Indian Health Service, "Workforce," *Issue Summary*, February 2001, <http://info.ihs.gov/infrastructure/ infrastructure4.pdf> (last accessed Sept. 25, 2003) (hereafter cited as IHS, "Workforce"). More recent figures list average physician longevity at nine years. These numbers compare with an average of two to two and a half years in the 1970s. *See also* Olson Testimony, Briefing Transcript, p. 126.

[279] Charles Grim, director, Indian Health Service, interview in Rockville, MD, July 21, 2003.

[280] IHS, "Workforce."

[281] Ibid.

registered nurses in inpatient and ambulatory care facilities, as well as pharmacists.[282] On a local level, conditions can be even worse. The director of the Division of Health for the Navajo Nation reported nursing vacancy rates exceeding 25 percent.[283]

Often, it is difficult to recruit and retain health care providers willing to live and work in remote locations.[284] The problem is especially acute in remote tribal communities, which lack the usual conveniences with which health care professionals are familiar.[285] Some of the specific obstacles to recruiting and retaining health professionals include lack of parity in pay,[286] insufficient or inadequate housing, lack of jobs for spouses, lack of community activities for youth, lack of health care for staff and families, insufficient opportunities for continuing education, and substandard educational systems.[287] These factors have each contributed to the historical difficulty IHS has experienced in staffing rural health facilities.[288]

Inevitably, a shortage of providers affects the quality of care. Gregg Bourland and Harold Frazier, former chairman and vice chairman, respectively, of the Cheyenne River Sioux Tribe in South Dakota, described the following situation at an IHS facility:

> In January and February 2002, the Eagle Butte Service Unit [in South Dakota] on the Cheyenne River Sioux reservation has been swamped with children with Influenza A, RSV [Respiratory Syntactical Virus], and one fatal case of meningitis. There are only three doctors on duty, one Physician Assistant, and one Nurse Practitioner. The only pediatrician is the Clinical Director who will not see any patients, even though there is a serious need for the services of a pediatrician. Several of these children have presented with breathing problems, high fever, and severe vomiting. The average waiting time at the clinic has been four and six hours. The average time at the emergency room is similar. Most babies have been sent home without any testing to determine what they have and with nothing but cough syrup and Tylenol. In at least three cases, the baby was sent home after these long waits two or more times with cough syrup, only to be life-flighted soon thereafter because the child could not breathe. The children were all diagnosed by the non-IHS hospital with RSV. . . . No babies have died yet, but the Tribe sees no

[282] Ibid.

[283] Roanhorse Testimony, Briefing Transcript, p. 143.

[284] Bird interview.

[285] U.S. Department of Health and Human Services, Indian Health Service, "IHS Awards $1.7 Million in Grants for Health Care Professionals in Indian Health Programs," Oct. 1, 2002, news release, <http://www.ihs.gov/PublicInfo/PublicAffairs/PressReleases/Press_Release_2002/Release_20_Recruitment_Grants_2002.asp> (last accessed Apr. 6, 2004) (hereafter cited as IHS, "$1.7 Million in Grants").

[286] *See* Taylor McKenzie, telephone interview, September 11, 2003; *see* LeRoy Jackson, USCCR Staff Director meeting with the Tribal Self-Governance Advisory Committee, Sept. 16, 2003. According to Richard Champany, clinical director at the Northern Navajo Medical Center in Shiprock, New Mexico, it is difficult for IHS to recruit providers in specialty and subspecialty fields such as emergency care, general surgery, orthopedics and anesthesiology because it is unable to pay competitive salaries. Richard Champany, telephone interview, June 29, 2004.

[287] U.S. Department of Health and Human Services, Indian Health Service, *Fiscal Year 2005 Budget Justification, Indian Health Professions*, p. IHS-116; IHS, "$1.7 Million in Grants."

[288] IHS, "$1.7 Million in Grants."

justification for waiting until this happens when these viruses are completely diagnosable and treatable.[289]

Improvements in recruiting, training, and compensation are necessary to reduce the shortage of health professionals at IHS facilities. To reduce staff shortages, IHS has been implementing a system of special pay, bonuses, and allowances.[290] IHS also has scholarship and loan repayment programs.[291] Both of these programs provide benefits to health professionals in exchange for serving in IHS.[292] Through IHS Indian Health Professions programs, IHS has been recruiting and retaining Native American health professionals. [293] These recruitment and retention activities are essential to staffing and managing IHS' health care delivery system.[294]

Under the authorization of IHCIA, IHS administers the IHS Health Professions Scholarship Program.[295] This program includes Section 103 Health Professions Preparatory Scholarship Programs for Indians, which authorizes two scholarship programs for Native American students in pre-professional education and pre-medicine or pre-dentistry education, and Section 104 Indian Health Professions Scholarship, which authorizes scholarships to Native American students in health professional schools.[296] In addition, authorized by Section 108 of IHCIA and funded through appropriations, IHS offers loan prepayment programs.[297]

Through scholarships and loan repayment programs, from 1981 to 2003, the total number of IHS professional staff members grew 51 percent and the number of Native American federally employed health professionals increased 230 percent.[298] The proportion of the Native American professional staff has increased 125 percent over the same period.[299] In 1981, 84 percent of the IHS health professional staff was non-Indian and by 2003, 64 percent of the staff was non-Indian and 36 percent Indian.[300]

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[289] 149 CONG. REC. S4109–47 (daily ed. Mar. 20, 2003) (statement of Sen. Daschle). As part of his statement, Senator Daschle referred to a letter from the Cheyenne River Sioux Tribe to IHS describing the situation at the Eagle Butte Service Unit. Senator Daschle also noted the following quality of care issues at the Eagle Butte Service Unit. The facility does not have an obstetrician; it is funded at 44 percent of the need calculated by the IHS; although Eagle Rock has a birthing room and 22 obstetrical beds, only two to three doctors are available to staff the clinic, hospital, and emergency room. *Id.*

[290] U.S. Department of Health and Human Services, Indian Health Service, *Fiscal Year 2005 Budget Justification, Indian Health Professions,* p. IHS-115.

[291] Ibid.

[292] Ibid., p. IHS-116.

[293] Ibid.

[294] Ibid.

[295] IHS, Interrogatory Response 45.

[296] Ibid.

[297] Ibid.

[298] U.S. Department of Health and Human Services, Indian Health Service, *Fiscal Year 2005 Budget Justification, Indian Health Professions,* p. IHS-119.

[299] IHS, "Workforce."

[300] IHS, Interrogatory Response 45; U.S. Department of Health and Human Services, Indian Health Service, *Fiscal Year 2005 Budget Justification, Indian Health Professions,* p. IHS-119.

In addition, acknowledging that a monetary incentive is sometimes necessary to retain health professionals in remote IHS facilities, HHS announced $1.7 million in new grants to tribal communities to assist in recruitment and retention programs. The objective of these grants is to recruit, place, and retain health professionals in areas with high vacancy and staff turnover rates.[301]

Despite signs of improvement through scholarships and loan programs and an increased awarding of grants, the need for qualified medical and nursing staff remains at a number of IHS facilities, particularly those in remote locations. While IHS data indicate an increase in professional staff in general, and Native Americans in particular, during the same period, IHS has continued to face increasing vacancy and turnover rates. Current vacancy rates are 25 percent for dental, 15 percent for nursing, 10 percent for medicine, and 9 percent for pharmacy.[302] According to data provided by IHS, in 2004, the total numbers of physicians, nurses, and dentists has decreased since 1993.[303] Furthermore, national trends indicate that the shortage of health professionals is increasing and without effective measures to recruit and retain health professionals, IHS will not be able to compete for an ever-decreasing number of available professionals.[304]

A review of IHS budget justifications from 1999 to 2004 illustrates that IHS has not made significant changes to existing recruitment and retention programs in at least the last five years. Total appropriation for Title I of IHCIA, Indian Health Manpower, for FY 1999 was $29,623,000; $30,491,000 for FY 2000; $30,486,000 for FY 2001; $30,565,000 for FY 2002; $31,114,000 for FY 2003; $30,774,000 for FY 2004; and an estimated $30,803,000 for FY 2005. In light of the insignificant changes in appropriations and the continued high vacancy and turnover rates at IHS, the existing recruitment and retention programs are not meeting the objective of reducing vacancy and turnover rates.

Misdiagnosis or Late Diagnosis of Diseases

One of the major problems created by the high turnover rate of providers is that patients do not receive consistent care. For patients who must seek regular treatment due to chronic health conditions, it is imperative that providers are aware of their medical history and the types of medication taken. Inconsistency among providers causes undue burden for the patient who must provide his or her medical history to each provider. In addition, inconsistency makes it difficult for the provider to diagnose the illness and make appropriate treatment decisions. Among the resulting problems are misdiagnosis and the assignment of incorrect treatment regimens. Furthermore, without an accurate medical history, providers may prescribe medications that interact negatively with previously prescribed medications or that produce allergic reactions. Therefore, continuity of care is an important indicator of quality care.

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[301] IHS, "$1.7 Million in Grants."

[302] U.S. Department of Health and Human Services, Indian Health Service, *Fiscal Year 2005 Budget Justification, Indian Health Professions*, p. IHS-116.

[303] IHS, Interrogatory Response 46. The numbers for pharmacists and optometrists increased during the same period. Ibid.

[304] *Indian Health Care Improvement Act: Hearing on S. 212 before the Senate Indian Affairs Comm.*, 107th Cong. (2001) (testimony of Michael Bird, American Public Health Association).

According to a 2002 study supported by HHS' Agency for Healthcare Research and Quality, continuity of care for Type 2 diabetes patients resulted in improved self-management of diet and glucose control.[305] Furthermore, explaining the benefits of continuity of care, the acting director of the Agency for Healthcare Research and Quality, Carolyn M. Clancy, M.D., has stated that continuity of care means that the provider knows the patient's past medical and personal history and other circumstances of the patient's daily life that affect one's health.[306] Accordingly, by developing a continuing relationship with the patient, the provider has the knowledge of the patient's entire history and the provider is better able to treat the patient.[307] Furthermore, continuity of care is also associated with greater efficiency in terms of increased satisfaction by patients and shorter hospital stays.[308]

Many Native American patients, due to high turnover rates, do not receive consistent care from one provider. According to a retired Lakota nurse, even though she knows to ask for proper medication and treatment, since suffering a heart attack, she has faced problems getting appropriate treatment. She explained that being seen by many different providers caused these problems.[309] Another story comes from a woman given a hysterectomy because of fibroid adhesive disease. She explained that despite the fact that her condition was written in her medical chart, she had to explain her condition to each doctor she saw. In one extreme situation, even though she explained to a new doctor that she had had a hysterectomy for her fibroid adhesive disease, the doctor did not believe her and forced her to undergo more testing despite the pain.[310]

Yet another story comes from Valerie Dupris Curley, who explains that many doctors at her IHS facility are temporary providers. Consequently, during each visit for her husband who has a chronic medical condition, they have to repeat his medical history for the providers.[311] At the Eagle Butte hearing, one of five health hearings held by the Cheyenne River Sioux Tribal Council to gather testimony on the delivery of IHS services to be submitted to the Senate Indian Affairs Committee,[312]one woman explained that for two years she was seen by different providers and misdiagnosed repeatedly. She was finally diagnosed with cancer. She expressed that "there should be doctors at IHS facilities that can stay and help the people."[313]

At the hearings held by the Cheyenne River Sioux Tribal Council, the most common complaint was misdiagnosis of illnesses by IHS providers. Another frequent concern was the late diagnosis of cancer. While early detection of cancer can increase the patient's chance of survival,

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[305] Michael L. Parchman, M.D., Dr. Pugh, Polly Hitchcock Noel, Ph.D., and Anne C. Larme, Ph.D., "Continuity of Care, Self-Management Behaviors, and Glucose Control in Patients with Type 2 Diabetes," *Medical Care*, vol. 40, no. 2, 2002, pp. 137–44.

[306] "Continuity of Care: How Important Is It to Your Health?" *Medical Reporter*, <http://medicalreporter.health.org/tmr0896/clancycare.html> (last accessed Apr. 6, 2004).

[307] Ibid.

[308] Ibid.

[309] Lois Spotted Bear, Cheyenne River Sioux Tribe Health Hearings, Eagle Butte Hearing, Mar. 12, 2002, p. 27 (hereafter cited as Eagle Butte Hearing).

[310] Joye Lebeau, Eagle Butte Hearing, pp. 22–23.

[311] Valeri Dupris Curley, Eagle Butte Hearing, p. 32.

[312] Rebecca Kidder, Eagle Butte Hearing, p. 5.

[313] Donna Talks, Eagle Butte Hearing, pp. 30–31.

the examples will illustrate the problem of late diagnosis at IHS facilities. For example, Lyle Jack testified at the Commission briefing about a cancer patient who for two years sought medical assistance for back pain. Each time the patient went to an IHS facility, he was sent home with pain medication without proper diagnosis. It was determined after two years of pain medication that the patient had cancer; he died three weeks after being diagnosed.[314] Another example of late diagnosis comes from a Native American woman from the Rosebud Reservation. Despite persistent stomach pain, she was diagnosed with heartburn. She later learned that she was suffering from fatal stomach cancer.[315]

Unfortunately, in Indian Country, the story of misdiagnosis is all too common. The IHS has acknowledged that cancer is diagnosed late in Indian Country.[316] In a telling statement, Lyle Jack explained that the reason why cancer is not diagnosed, or diagnosed late, is that IHS does not have providers trained in its detection.[317] Because of the lack of cancer specialists, many treatable cancers go undiagnosed or diagnosed too late.[318]

Dr. Grim cited a lack of resources and the remoteness of facilities as reasons for misdiagnosis or late diagnosis of cancer.[319] Dr. Olson of IHS testified that one of the reasons for late diagnosis is the providers' failure to screen for preventable diseases early.[320] While additional resources would remedy some of the problems related to misdiagnosis, failure to screen early for preventable diseases is more than just a resource problem. Given the lack of funding or resources, IHS must improve training for current providers or recruit more qualified providers to ensure that providers take early screening measures and follow-up with patients. Dr. Grim placed the onus on the shoulders of Native Americans, urging them to "go back, and that's not always easy. They need to continue to ask questions of their provider until they have them adequately answered."[321] Before asking the patients to follow-up with providers, providers must be better trained to notice early signs of more serious conditions and to take appropriate preventive measures, whether screening for diseases or increasing the monitoring of patients' conditions.

The causes of misdiagnosis or late diagnosis are twofold. First, as explained, lack of continuity of care by primary providers leads to misdiagnosis or late diagnosis. For example, the Eagle Butte cancer patient identified above attempted to explain her medical condition for two years to each new provider she saw, yet never received proper screening, resulting in late diagnosis of cancer.[322] Second, the lack of competent providers leads to misdiagnosis or late diagnosis. Providers sometimes may not have the proper training to look for early warning signs of more serious conditions. High turnover rates contribute to this lack of proper training.

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[314] Jack Testimony, Briefing Transcript, p. 56.

[315] Tom Daschle, "Adequate Indian Health Funding Not Unrealistic," *Argus Leader*, May 7, 2004.

[316] Olson testimony, Briefing Transcript, p. 158.

[317] Jack testimony, Briefing Transcript, p. 56.

[318] Ibid.

[319] Grim testimony, Briefing Transcript, p. 109.

[320] Olson testimony, Briefing Transcript, p. 158.

[321] Grim testimony, Briefing Transcript, p. 108.

[322] Donna Talks, Eagle Butte Hearing, pp. 30–31.

According to IHS, based on the results of a study conducted in 1999–2001, which found frequent delays in treatment from the time of diagnosis, and other surveys and focus groups, IHS has made efforts to place Native American providers and staff into early detection programs and to encourage clinicians to get their patients to treatment more rapidly.[323] Furthermore, IHS' Cancer program has training activities aimed at early detection and early treatment, including a cancer survivors' support group training, Native Researcher's Cancer Control Training, close partnership with the CDC National Breast and Cervical Cancer Early Detection Program, colposcopy training for IHS primary care physicians, and cancer awareness training for Community Health Representatives.[324] Unfortunately, IHS did not explain in detail how these training programs would have an impact on the early detection and early treatment of cancer. At this stage, IHS does not have detailed information about cancer incidence rates.[325] IHS has begun over the past year to engage many of the state members of the CDC-funded National Program of Cancer Registries in a data match to improve the ascertainment of race in those registries.[326] It hopes to use the resulting data to analyze issues such as stage at diagnosis and survival rates.[327] As the information provided by IHS indicates, IHS does not have detailed cancer-related information to help it set its cancer prevention and early detection programs or policies.

Furthermore, despite some cancer training activities, both Dr. Grim and Dr. Olson of IHS stated at the Commission briefing that IHS lacks the resources necessary to provide appropriate screening equipment and adequate training.[328] Based on the information provided by IHS and other sources indicating high incidence of late diagnosis of cancer, it does not appear that IHS has taken appropriate measures to detect and screen for serious illnesses early enough to prevent treatable conditions from becoming untreatable. This failure to properly diagnose and treat existing conditions is an indication of a lack of quality care having a detrimental effect on the overall health outcomes of Native Americans.

Conclusion

Native Americans face barriers to gaining access to health care. As Chapter 2 explained, there are social and cultural barriers such as discrimination, bias, and a lack of culturally competent care. In addition, the system itself creates barriers. As this chapter has explored, structural barriers limit access to care. Providing additional funding will certainly address some of the resource issues. However, structural problems involving IHS management, operation, and administration of its health care system go beyond funding appropriation and allocation. Operational decisions by IHS on where to place facilities and what types of services to provide affect access. Lack of meaningful tribal participation and input on operational decisions concerning the location of the facilities and the types of services to be provided negatively affects Native American patients. Native Americans, limited by impassable road conditions and lack of transportation, face real physical access barriers in reaching IHS facilities that are too far

[323] IHS, Interrogatory Response, 25.

[324] Ibid.

[325] Ibid.

[326] Ibid.

[327] Ibid.

[328] Grim testimony, Briefing Transcript, p. 109; Olson testimony, Briefing Transcript, p. 158.

away from their homes. Furthermore, the types of services they need are not always provided at the IHS facility they use and, therefore, Native Americans are forced to seek contracted services or travel long distances to access services.

In addition, even when Native Americans are able to get to IHS facilities, they face barriers caused by aging facilities and long wait times. On average, IHS facilities are much older than non-IHS facilities and, often, these aging facilities are accompanied by haphazard or insufficient use of space. Long wait times at IHS facilities make it even more difficult for patients to gain access to care. While walk-in patients may crowd waiting rooms and cause delays for providers, IHS' management and operation decisions must take into consideration that, due to transportation issues, some Native Americans are forced to seek walk-in services and therefore, IHS must take measures to address long wait times.

Limitations on access are intensified by the lack of qualified providers at IHS facilities. The IHS experiences high provider turnover, leaving Native Americans without reliable providers and consistent services, and affecting the quality of health care they receive. Insufficient recruiting and retention efforts by IHS contribute to high turnover and vacancy rates. As a result, IHS cannot ensure that adequate services are provided to Native Americans.

Even more troubling is the misdiagnosis and late diagnosis of diseases such as cancer. As IHS admits, IHS providers do not always screen for preventable diseases early enough to provide timely treatment. Cancer death rates among Native Americans are unnecessarily high as a direct result of IHS providers failing to take early preventive measures to detect and treat cancer. These barriers, whether a result of physical access or quality issues, lead to the presence of disproportionate health disparities among Native Americans. Accordingly, the Commission makes the following recommendations:

- The IHS should re-evaluate its current Contract Health Services (CHS) eligibility requirement and adopt an eligibility requirement that allows all qualified Native Americans from federally recognized tribes to receive CHS regardless of their place of residence. The change in the eligibility requirement should come with an appropriate increase in funding to ensure that the resulting growth in CHS user population does not further weigh down an already overburdened system.

- The IHS should provide technical training and assistance to Native American tribes lacking the resources and capacity to meaningfully and effectively participate in consultations with IHS.

- The IHS should routinely assess and evaluate its tribal consultation and participation processes. In addition, the effective use of tribal consultation should be made a critical element in the annual performance evaluation of IHS managers to ensure that IHS managers are providing tribes meaningful and effective participation in all decision-making processes that affect Native American health care.

- The IHS should standardize and coordinate its data collection efforts with tribes participating in self-governance contracts or compacts to ensure that comprehensive Native American health data are collected. The collection procedures and criteria adopted

by IHS should be established in consultation with tribes. Standardized and coordinated data collection will make for more informed Indian health policies and initiatives.

- The IHS should accelerate efforts to make telemedicine widely available and easily accessible for communities in remote areas. The IHS telemedicine programs should be carefully tailored to overcome the challenges related to the lack of affordable telecommunications in some areas, reluctance on the part of service providers to utilize telemedicine technology, and concerns about providing culturally sensitive health services.

- The IHS should redesign operating policies to reflect the reality that many Native Americans have limited access to reliable transportation and, as a result, have limited access to IHS health facilities. To address this problem, IHS should use more "walk-in" services, allowing walk-in appointments as part of its regular health delivery system.

- The IHS should implement initiatives to reduce wait times at its facilities. These initiatives should include redesigning or reconfiguring waiting areas and examining rooms to reduce overcrowding and increase productivity and efficiency; hiring more staff to reduce workload; training staff on time management; and increasing productivity and efficiency.

- The IHS should revise its recruiting and retention programs and take proactive measures to recruit and retain qualified providers. The revised IHS recruitment and retention programs should include tailoring the programs to meet the specific recruiting and retention needs of various IHS Service Areas by providing competitive pay to providers in areas where parity in pay is an issue; providing adequate housing or supplementing housing costs to address lack of adequate housing; and providing special incentives for providers in rural areas to compensate and address the lack of lifestyle choices in rural areas.

- The IHS facilities should be properly equipped with screening and diagnostic equipment to provide early detection of disease. Early detection will reduce mortality rates, as well as medical costs, over the long term. In addition to screening and diagnostic equipment, adequate training for providers must be provided.

Chapter 4: Financial Barriers Limiting Native American Access to Health Care and Contributing to Health Disparities

The testimony, research, and interviews conducted in support of this report show that inadequate federal funding is an important obstacle to adequate health care and eliminating disparities in health status for Native Americans. This report is not the first time the Commission has identified this obstacle. In *A Quiet Crisis*, the Commission concluded that "the anorexic budget of the IHS [Indian Health Service] can only lead one to deduce that less value is placed on Indian health than that of other populations."[1] Speaking for the administration, the Assistant Secretary of Minority Health for the Department of Health and Human Services (HHS) explained that "barriers to adequate health care include underfunding or complete lack of funding."[2] In arguing for increases in funding, Senator Tom Daschle related a story that gives life to the statement that the level of underfunding is disastrous.

> Several years ago, a stillborn baby was delivered in Eagle Butte. A simple ultrasound would have prevented the death of this full-term, healthy baby: the umbilical cord was wrapped around his neck. No ultrasound was performed, even though the baby's heart rate was dangerously low, because the IHS, due to budget constraints, allows only one ultrasound per pregnancy, and the baby's mother already had hers.[3]

The need for additional funding is particularly well supported by advocates for Native American health care, who have developed a variety of measurements to verify the inadequacy of present funding levels. Over the years, they have made the following arguments to the President and Congress when requesting additional funding, which are discussed later in this chapter:

- Annual per capita health expenditures for Native Americans are only 60 percent of the amount spent on other Americans under mainstream health plans.
- Annual per capita expenditures fall below the level for every other federal medical program and standard.
- Annual increases in IHS funding have failed to account for medical inflation rates and increases in population.
- Annual increases in IHS funding are less than those for other HHS components.
- Annual increases have effectively been reduced to reflect increased collection efforts despite express congressional intent that appropriations not be reduced.

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[1] U.S. Commission on Civil Rights, *A Quiet Crisis: Federal Funding and Unmet Needs in Indian Country*, July 2003, p. 49 (hereafter cited as USCCR, *A Quiet Crisis*).

[2] Dr. Charles W. Grim, Indian Health Service, "Eliminating Disparities Is More Than an Access Issue" (speech delivered at the 32nd annual Meeting of the Association of American Indian Physicians, Santa Fe, NM, Aug. 4, 2003), <http://www.ihs.gov/PublicInfo/PublicAffairs/Director/2003_Statements/FINAL-AAIP_August_2003.pdf> (last accessed Feb. 9, 2004).

[3] Tom Daschle, "Adequate Indian Health Funding Not Unrealistic," *Argus Leader*, May 7, 2004, p. 9B.

Examined individually, these measurements express in clear terms that funding levels are inadequate. When examined together, the conclusion is unmistakable that current funding levels are far below that necessary to maintain basic health services and that the federal government has failed to satisfy its explicit trust obligation. The first section of this chapter addresses affordability as measured by government spending, including a detailed examination of several methods for measuring the adequacy of funding levels.[4] This discussion will be followed by an analysis of specific identifiable funding needs for contract health services, contract support costs, and the Urban Indian Health Program, as well as an evaluation of certain administrative issues surrounding the financing of Native American health care. These administrative issues include the frequently misunderstood term "entitlement," rules for the distribution of funds among tribes and regions, and rules for the administration of designated appropriations. The second section of this chapter isolates the insurance component of health care financing. Specifically, it examines the various barriers that produce startling numbers of uninsured Native Americans and how those barriers have a detrimental influence on the affordability of and the access to health care. The chapter closes with the identification of findings and specific recommendations to address them. Funding background is provided before the examination of financial barriers to place the discussion in context.

Funding Background

As the primary health care provider for Native Americans, IHS receives the vast majority of funds appropriated for that purpose. For FY 2005, the President's budget request included $2.97 billion for IHS, just 4.4 percent of a $66.8 billion HHS discretionary budget and an even smaller 0.5 percent of the overall HHS budget of $580 billion.[5] While other HHS components and programs provide limited health-related services for Native Americans, their Native American expenditures are equal to approximately 0.5 percent of IHS spending on Native Americans, less than $20 million.[6]

The FY 2005 budget request includes a $45 million increase, which is only 1.6 percent above FY 2004 enacted levels.[7] To some extent, at least in the allocation of additional funds, the increase reflects priorities established through tribal consultation, including increases to cover pay raises and inflation, thereby protecting the current level of services, and greater funding for preventive services.[8]

Another HHS agency, the Centers for Medicare & Medicaid Services (CMS), directly funds health care services for Native Americans who are enrolled in Medicaid, Medicare, or the State Children's Health Insurance Program when their care is provided through IHS or tribal

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[4] These individual methods parallel the arguments identified above for establishing the inadequacy of funding levels.

[5] U.S. Department of Health and Human Services, *Fiscal Year 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-12 (hereafter cited as HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*). *See also* Northwest Portland Area Indian Health Board, *Priority One: The FY 2005 Indian Health Service Budget: Analysis and Recommendations*, Mar. 8, 2004, pp. 42–43.

[6] *See* USCCR, *A Quiet Crisis*, Tables 2 and 3 of Chapter 3 (citing the Budget of the United States Government, Fiscal Year 2004, Historical Tables, Table 5.4, pp. 103–04).

[7] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-12.

[8] Ibid.

facilities.[9] The President's FY 2005 budget request estimates Medicaid and Medicare expenditures of $544 million,[10] or a very small 0.1 percent of the combined annual Medicaid and Medicare budget of $473 billion.[11] CMS funds spent on Native Americans are seen as IHS collections or reimbursements, rather than budgeted appropriations. When IHS budget appropriations are combined with collections from CMS and private, third-party insurers, the total composes the program-level funding for IHS and provides a better picture of the overall federal government spending on Native American health care. For FY 2005, the President's budget estimates reimbursement in excess of $598 million, for a total IHS program-level funding of almost $3.7 billion.[12]

Even with program-level funding boosted by third-party collections, the end result is a rationed system. The IHS acknowledges this reality in its budget justification, explaining that its system "explicitly rations care, deferring and denying payment for medical services that are thought to be of lower priority."[13] To what degree rationing is a problem is discussed in detail in the Contract Health Services section. First, it is necessary to address the myth surrounding the gaming industry in Indian Country and its contribution to the continued shortfalls in federal funding and the resulting system of rationed care.

Because the Native American gaming industry has grown to encompass 220 tribes, 377 facilities, and more than $16 billion per year in revenue, a perception exists that Indians have been given everything they need and that federal "handouts" are no longer necessary.[14] This perception is inaccurate on several levels. First, it ignores the federal trust obligation discussed earlier in this report. Second, it overstates the magnitude and impact of gaming profits. A report prepared for the American Indian Program Council provides a clearer picture of the impact of casinos in Indian Country:

- Only half of all tribes have casinos.
- Thirty-nine casinos produced the majority of casino-generated income. More specifically, 39 percent of casinos accounted for 66 percent of revenue.
- Casinos in five states, with more than half the total Native American population, accounted for less than 3 percent of all casino revenue.
- Casinos in three states, with only 3 percent of the Native American population, accounted for more than 44 percent of all casino revenue.
- Dozens of casinos barely break even because of inadequate size or location.[15]

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[9] CMS also provides funding for Native Americans treated at non-IHS facilities. This funding was not included as credible data was unavailable.

[10] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-12.

[11] Indian Health Service, "President's Fiscal Year 2004 Budget Request." *See also* Northwest Portland Area Indian Health Board, *Priority One: The FY 2005 Indian Health Service Budget: Analysis and Recommendations*, Mar. 8, 2004, p. 43.

[12] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-2.

[13] Ibid., p. IHS-27.

[14] James Brosnan, "Indian Gaming Surges, States Seeking Larger Cut," *Scripps Howard News Service*, Apr. 3, 2004.

[15] Richard Anzures, "Time Special Report: Portrays Misconception of Indian Gaming and Tribal Sovereignty," <http://www.aipc.osmre.gov/GamingReport.htm> (last accessed May 27, 2004).

The overall effect is that only a relatively small number of tribes have been very successful—successful enough to establish health care systems independent of federal aid. For most tribes, gaming has brought increased administrative, legal, and lobbying expenses along with impressive gains for non-Indian investors and state governments who have taken as much as 16 percent of revenue.[16] After other expenses are covered, some percentage of the successful tribes has appropriately applied some portion of their increased revenue to health care. Nevertheless, the vast majority of tribes, and Native Americans, must continue to rely on the inadequate funds appropriated to the IHS.

Measurements of Funding Adequacy

The adequacy of funding for Native American health care was central to recent hearings before the Senate Committee on Indian Affairs. On February 26, 2003, and March 5, 2003, the committee conducted hearings on the President's FY 2004 budget request for Indian programs. The hearings addressed a wide array of Native American programs, including the Indian Health Service. The four panelists represented the National Congress of American Indians, the National Indian Health Board, the urban Indian community, and the Indian Health Service. Over the course of the two hearings, the panelists developed two competing images for the committee. The first image, from Dr. Charles W. Grim, director of the Indian Health Service, described an increasing budget, demonstrative of government commitment to high-quality health care for Native Americans.[17] It is important to note that Dr. Grim frequently hedges his optimism with the phrase "within the scope of national priorities."[18] The second image, from the three advocates, described a marginal budget increase, woefully inadequate for bridging the divide between the current funding level and that necessary for Native Americans to receive the same medical care as average Americans.[19] The five methods of analysis characterized below will help explain how the same system could be described using two vastly differing images.

Level of Unmet Need Calculation

The first of these methods is the level of unmet need calculation. It is important to note that the level of unmet need calculation is a government mechanism, created independent of the motivation to advocate for additional funding. Significantly, it draws conclusions similar to those drawn by the most forceful advocates for Native American health care. Specifically, the IHS was funded at 52 percent of the level appropriate for the average American in 2003, leaving an unmet need of more than $3 billion.[20] This methodology will be explained in detail, first, to establish a

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[16] Ibid. *See also* James Brosnan, "Indian Gaming Surges, States Seeking Larger Cut," *Scripps Howard News Service*, Apr. 3, 2004.

[17] *See generally The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Dr. Charles W. Grim, director, Indian Health Service).

[18] Dr. Charles W. Grim, "An Indian Health Update" (remarks at the Midwest Alliance of Sovereign Tribes Impact Week Meeting, Mar. 22, 2004).

[19] *See generally The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statements of Tex Hall, president, National Congress of American Indians; Julia Davis-Wheeler, chair, National Indian Health Board; and Kay Culbertson, executive director, Denver Indian Health and Family Services).

[20] U.S. Department of Health and Human Services, Indian Health Service, "FY 2003 IHCIF—Area Summary," <http://www.ihs.gov/NonMedicalPrograms/lnf/2003/AreaAllowanceSummary.pdf> (last accessed July 7, 2003).

degree of credibility and, second, to provide some sense of margin of error. No system is without its critics; the level of unmet need calculation is no exception. A summary of criticisms presented by the Alaska Native Health Board is included as an additional check on the credibility of using the unmet need calculation to evaluate the annual IHS budget.

Several times throughout the congressional hearings referenced above, mention was made of the unmet need calculation. It is this mechanism and its use of a disparity index that led to the conclusions made by those testifying that the IHS budget falls short of the $18 billion necessary to extend IHS service to all Native Americans.[21] The explanation below will evaluate that assertion and the FY 2005 budget request.

The unmet need calculation was originally created to address distribution issues within the Native American health care system. Historically, the IHS has been challenged for its inequitable distribution of resources among health services and facilities for the various tribes.[22] The distribution controversy reached a head during *Rincon Band of Mission Indians v. Harris*,[23] where a group of California Indians sought redress for disparate funding levels for Indian health care in California. At the time, less than 2 percent of total IHS funding had been allocated to California despite that approximately 10 percent of the IHS user population lived in California.[24] IHS had been using a priority system that emphasized program continuity to distribute any remaining funds. The court ruled in favor of the plaintiff Indians, finding that the system failed to set a rational and proper standard for the equitable distribution of Snyder Act funds and mandating systemic improvements to resolve the iniquities.[25] In response to the court order, IHS developed an equity fund as a proportion of annual appropriations, referred to as the Indian Health Care Improvement Fund (IHCIF). Distribution of the IHCIF is based on the unmet need of individual tribes.[26] Currently, the IHS "Level-of-Need Funding Workgroup" establishes the level of unmet need, now measured as the FEHBP Disparity Index (FDI).[27]

The FDI is simply the ratio of funds spent on Native American health care for a specified locale, compared with the benchmark cost for mainstream benefits, or the funds spent on the "average" American, as measured by the level of spending in the Federal Employee Health Benefits Program (FEHBP).[28] The lower the ratio for a specified location, the more funding lags for Native Americans in that location, and the higher the proportion of new funding to be

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[21] *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statements of Tex Hall, president, National Congress of American Indians, p. 7, and Julia Davis-Wheeler, chair, National Indian Health Board, p. 5). This number includes $9–10 billion in annual expenditures and $9 billion one-time facilities construction expenses. *See also* Northwest Portland Area Indian Health Board, *FY 2004 IHS Budget Analysis*, p. 2.

[22] *See generally* Rose L. Pfefferbaum et al., *Providing for the Health Care Needs of Native Americans: Policy, Programs, Procedures and Practices*, 21 AM. INDIAN L. REV. 211 (1997). Pfefferbaum reports that 1993 per capita IHS allocations ranged from a high of $1906 in Alaska to a low of $525 in Portland. Pfefferbaum at 242.

[23] Rincon Band of Mission Indians v. Harris, 618 F.2d 569 (9th Cir. 1980).

[24] *Id.* at 571.

[25] *Id.* at 572.

[26] Problems remain with the adequacy of this distribution mechanism.

[27] FEHBP—Federal Employee Health Benefits Program.

[28] U.S. Department of Health and Human Services, "FEHBP Disparity Index," <http://www.ihs.gov/Nonmedical programs/lnf> (last accessed July 14, 2003) (hereafter cited as HHS, "FEHBP Disparity Index").

allocated. Once the FDI is determined for all individual locations, the fiscal year IHCIF can be allocated. The threshold to qualify for the IHCIF is a score of 60 percent or less on the FDI. Funds are allocated to all tribes falling below that threshold level.[29]

The FDI is calculated using a complicated formula based on a series of assumptions and comparisons.[30] The first step is to determine the benchmark cost for mainstream benefits using an actuarial model. The benchmark (or health care spending on the average American) is the FEHBP, adjusted for numerous geographical and demographic differences. The second step combines the per capita funds available from IHS sources in that region and the funds available from all non-IHS resources to obtain the funds spent on health care for Native Americans.[31] A 1991 IHS survey set this non-IHS resource figure at 25 percent of the total amount spent for Indian health care.[32] The FDI is the ratio of funds available for Native American health care relative to the FEHBP benchmark.

The difference between the funds available and the benchmark is the unmet need. In FY 2000, the federal benchmark was $2,980, the average nationwide level of funding available for Native Americans was $1,728, and the average FDI was 58 percent.[33] Since 2000 the FDI had fallen to a level of 52 percent in 2003.[34]

In addition to its role in the distribution of the IHCIF, the FDI has become a useful tool for evaluating the overall Indian health system. For example, the figures illustrated above demonstrate the funding shortfall on an individual level. Since the FDI is a ratio, it applies equally well at the program level. When the IHS funding level is divided by the FDI, the result is the federal benchmark funding level for a program with the number of users in the IHS program.

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[29] HHS, "FEHBP Disparity Index." Equitable distribution of resources is an ongoing problem. *See* Duane Jeanotte testimony before the U.S. Commission on Civil Rights, briefing, Albuquerque, NM, Oct. 17, 2003, transcript, p. 209 (hereafter cited Briefing Transcript); Indian Health Service, "Speaking with One Voice: IHS, Tribes, Urban" (Draft Report on the Indian Health Service Regional I/T/U Consultation Meeting held Feb. 12, 1999 in Reno, Nevada); U.S. Congress, Office of Technology Assessment, *Indian Health Care*, OTA-H-290, April 1986), p. 155.

[30] HHS, "FEHBP Disparity Index."

[31] Ibid.

[32] This value is based on a 1991 survey. It reflects neither the rapid growth in the IHS user population since 1991, nor the rapid increase in collection efforts on the part of IHS and CMS. By some estimates, as many as 40 percent of Native Americans are eligible for Medicaid, with more eligible for Medicare and SCHIP; as many as 50 percent have private insurance, yet IHS estimates that only 25 percent of the money spent on Native American health care comes from non-IHS sources. *See* Kaiser Commission on Medicaid and the Uninsured, *Key Facts*, June 2000, <http://www.kff.org/content/2000/1525/American percent20Indians.pdf> (last accessed July 14, 2003). A recent CMS survey explains the extent to which CMS and IHS are unaware of the actual numbers of Native Americans eligible and/or enrolled in public health insurance programs. *See* Kathryn Langwell et al., *American Indian and Alaska Native Eligibility and Enrollment in Medicaid, SCHIP, and Medicare—Estimating Eligibility and Enrollment: A Methodological and Data Exploration*, December 2003, pp. 1–3 (hereafter cited as Langwell, *Eligibility and Enrollment in Medicaid*).

[33] HHS, "FEHBP Disparity Index."

[34] U.S. Department of Health and Human Services, Indian Health Service, "FY 2003 IHCIF—Area Summary," <http://www.ihs.gov/NonMedicalPrograms/lnf/2003/AreaAllowanceSummary.pdf> (last accessed July 7, 2003).

$$\text{FDI} = .52 = \frac{\text{IHS average}}{\text{FEHBP average}} = \frac{\text{IHS Total}}{\text{FEHBP avg. x \# of IHS users}}$$

Unmet Need for Individuals = FEHBP avg. - IHS avg.

Unmet Need for Program = FEHBP avg. x # of IHS users – IHS total

The President's FY 2005 budget request for Indian programs proposes program-level funding of $3.7 billion, including $3.2 billion for health services and the remainder for health care facilities.[35] Applying the FDI of 52 percent produces an unmet need in the range of $3 billion for FY 2004. This figure reflects only the unmet need for the IHS user population, not for the total Native American population.

The FDI measurement system is not without its critics. In addition to possible errors in the 25 percent non-IHS resource figure, the Alaska Native Health Board has completed a report on its dissatisfaction with the Level-of-Need Funding (LNF) Workgroup. The report identifies the following deficiencies: the formula fails to account for prevention and public health strategies, including facilities construction; the formula limits its health status indicators to the coarse indicators on birth, death, and poverty rates; and its efficiency factors fail to account for the problems associated with the small and extremely isolated areas common in Alaska, where market conditions and comparisons simply do not apply. If these deficiencies were factored into the level of funding needed, the level of unmet need would be substantially greater. In addition, in general terms, the Alaska Native Health Board believes that the LNF methodology gives the false impression that an insurance model will "fix" problems better suited to a public health model.[36]

Nevertheless, the LNF methodology is an accepted government measurement of necessary health care funding, a measurement making the unequivocal statement that Native American health care is grossly underfunded. Significantly, the unmet need calculation includes only the Native Americans using IHS. Including all Native Americans would greatly expand the level of unmet need. In fact, the Northwest Portland Area Indian Health Board, a recognized leader in budget evaluation in the Native American community, estimates that providing the entire Native American population with the care at the level provided to federal employees would require $8–9 billion in increased annual funding, as calculated under LNF methodology.[37]

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[35] Program-level funding includes $2.99 billion from standard appropriations and $700 million from public and private insurance collections and a special diabetes appropriation. *See* HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-2.

[36] Alaska Native Health Board, "Public Health and Isolation: The Missing Elements of LNF," October 2000, <http://www.anhb.org/documents/ANHB_LNF_Report.pdf> (last accessed July 7, 2003).

[37] Northwest Portland Area Indian Health Board, "FY 2004 IHS Budget Analysis," p. 2 (hereafter cited as NPAIHB, "FY 2004 IHS Budget Analysis"). The remainder of the $18 billion requested before the Senate Indian Affairs Committee is accounted for by a one-time expenditure of $10 billion for facilities.

Rate of Increase Relative to Inflation

The preceding section made clear that funding levels are inadequate by the government's own standards. This government failure is compounded by the failure of annual increases to even keep pace with inflation and population growth. Current estimates place the growth rate of the IHS user population at 1.8 percent per year.[38] Furthermore, the fastest growing segments of the population are the very young and the elderly, both of which carry the highest burden of disease.[39]

The overall IHS budget has grown at a rate slightly below the rate of inflation over the past several years. The $2.97 billion budgeted for FY 2005 appropriations represents an increase of 1.6 percent from FY 2004.[40] This follows an increase of only 2.6 percent in FY 2004, an amount far below that needed to maintain the current level of services.[41] As recently as FY 2000, annual appropriations included a line item to compensate for inflation. Though less than the calculated inflation rate, Congress at least attempted to maintain constant spending levels. Since FY 2000, not one dollar has been allocated specifically to address the rising cost of health care for Native Americans.[42] In FY 2005 alone, this shortfall will amount to more than $50 million.[43]

With only limited increases proposed, actual spending power will continue to decline due to the high medical inflation rate, the moderate health services and facilities inflation rates, and the significant population growth identified above.[44] The Northwest Portland Area Indian Health Board estimated that $360 million, a full 12.4 percent increase, would have been needed in FY 2004 simply to cover current services and mandatory costs.[45] Those figures, when updated, will certainly be larger for FY 2005 as the gap continues to widen.

As an additional measure of the effectiveness of the "growing" budget, the HHS budget justification breaks down the allocation of individual increases, including an analysis of the services those increases provide. The list below represents $34 million of the $45 million budgeted increase, yet not one dollar of that increase produces an increase in available services:

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[38] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-85.

[39] Ibid.

[40] Ibid., p. IHS-12.

[41] NPAIHB, "FY 2004 IHS Budget Analysis," p. 2.

[42] U.S. Department of Health and Human Services, Indian Health Service, Response to the Commission's Interrogatory 19, April 2004 (hereafter cited as IHS, Interrogatory Response).

[43] Ibid.

[44] For FY 2004, the Northwest Portland Area Indian Health Board estimates the medical inflation rate for CHS services at 12.5 percent, the health services inflation rate at 7.5 percent, the facilities inflation rate at 4.0 percent, and the population growth at 2.1 percent of the health services account. *See* NPAIHB, "FY 2004 IHS Budget Analysis," p. 13. The differences between the medical inflation rate and the health services and facilities inflation rates are obtained by estimating the percentage of the expense subject to the respective medical and general inflation rates. *See* Ed Fox, executive director of Northwest Portland Area Indian Health Board, e-mail, Apr. 17, 2004.

[45] NPAIHB, "FY 2004 IHS Budget Analysis," pp. 9, 15. Mandatory costs include $19.6 million for federal pay increases, $16 million for tribal pay increases, and $25.5 million to fund staffing and operating costs for new facilities. *See also The President's FY 2004 Budget for Indian Programs Before: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Dr. Charles W. Grim, interim director, Indian Health Service).

- The budget for dental health services increases by $5.7 million, yet 92,000 fewer services will be provided.[46]
- The budget for mental health services increases by $2.5 million, yet 7,700 fewer services will be provided.[47]
- The budget for alcohol and substance abuse treatment increases by $3.4 million, yet 29,000 fewer outpatient visits will be provided.[48]
- The budget for contract health services increases by $18 million, yet fewer general medical and surgical hospitalizations will be provided, though the number of outpatient visits will increase by 1,175.[49]
- The budget for public health nursing increases by $3 million, yet 13,000 fewer patient visits will be provided.[50]
- The budget for contract health representatives increases by $1.4 million, yet 99,000 fewer tribally operated services will be provided.[51]

For most of the increases listed above, the majority of the funding increase is to cover salary increases. In some cases, a portion is applied to the staffing of new facilities. No specific funding is provided for the effects of inflation on supplies and facilities.[52]

FY 2005 is not the first year with limited budget increases. The graphs below clearly illustrate the financial trends afflicting Native Americans. The first of the two illustrates that the per capita spending power for IHS appropriations, in 1996 dollars, dropped from a high of $1,439 in 1991 to a low of $1,197 in 1998.[53] IHS attributes most of this drop to medical inflation.[54]

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[46] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-53.

[47] Ibid., p. IHS-59.

[48] Ibid., p. IHS-67.

[49] Ibid., p. IHS-75.

[50] Ibid., p. IHS-83.

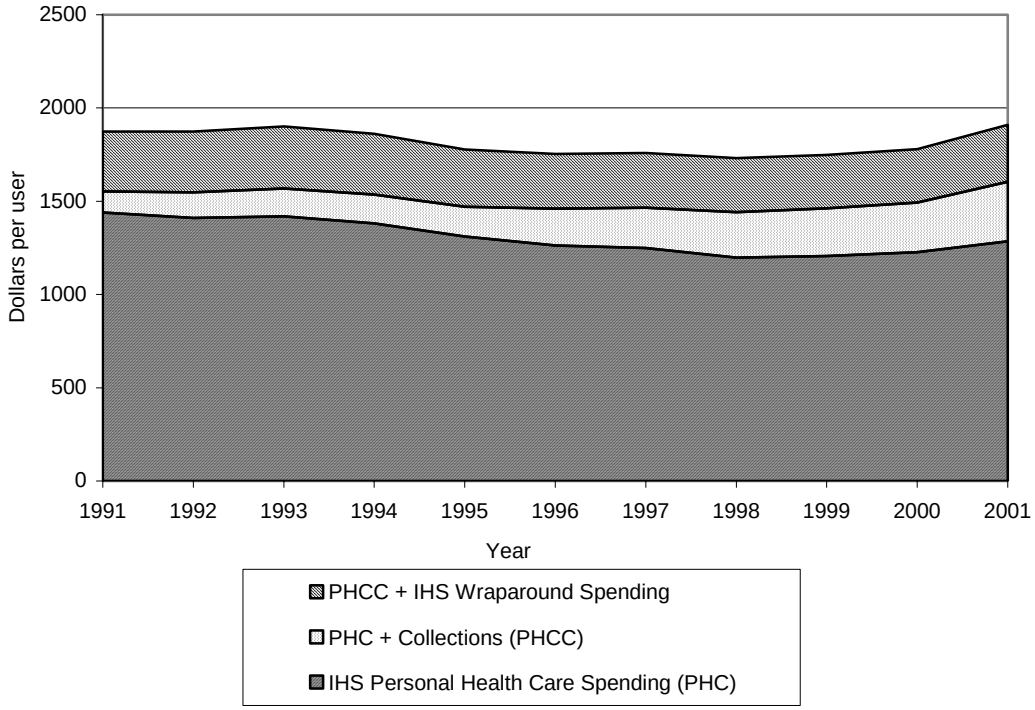
[51] Ibid., p. IHS-95. Similar IHS figures for the FY 2004 budget indicate a 6 percent reduction in inpatient admissions, a 4 percent reduction in outpatient visits, a 3.5 percent reduction in dental services, and a 1 percent reduction in CHS outpatient visits. *See* IHS Business Plan as cited in *The President's FY 2005 Budget for the Indian Health Service: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2004) (statement of Don Kashavaroff, Alaska Native Tribal Health Consortium).

[52] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, pp. IHS-53, 59, 67, 75, 83, 95.

[53] U.S. Department of Health and Human Services, Indian Health Service, "10 Year Expenditure Trends," <http://www.ihs.gov/nonmedicalprograms/ihdt2/bd/IHS10 yr.pdf> (last accessed June 21, 2004). IHS figures show that, as of 2003, the level for actual per user buying power had decreased 15 percent over 12 years, with slight decreases on all charted figures in the table.

[54] U.S. Department of Health and Human Services, Indian Health Service, *Revenues and Buying Power Trends: Indian Health Service 2001–2003* (Presentation of Mar. 4, 2003) (hereafter cited as IHS, *Revenues and Buying Power Trends: Indian Health Service 2001–2003*).

Figure 2: Ten-Year Trends in IHS Buying Power Per Capita



Source: Indian Health Service "Ten Year Funding Trends," <www.ihs.gov/nonmedicalprograms/ihdt2/Oldindex.asp> (accessed July 3, 2003).

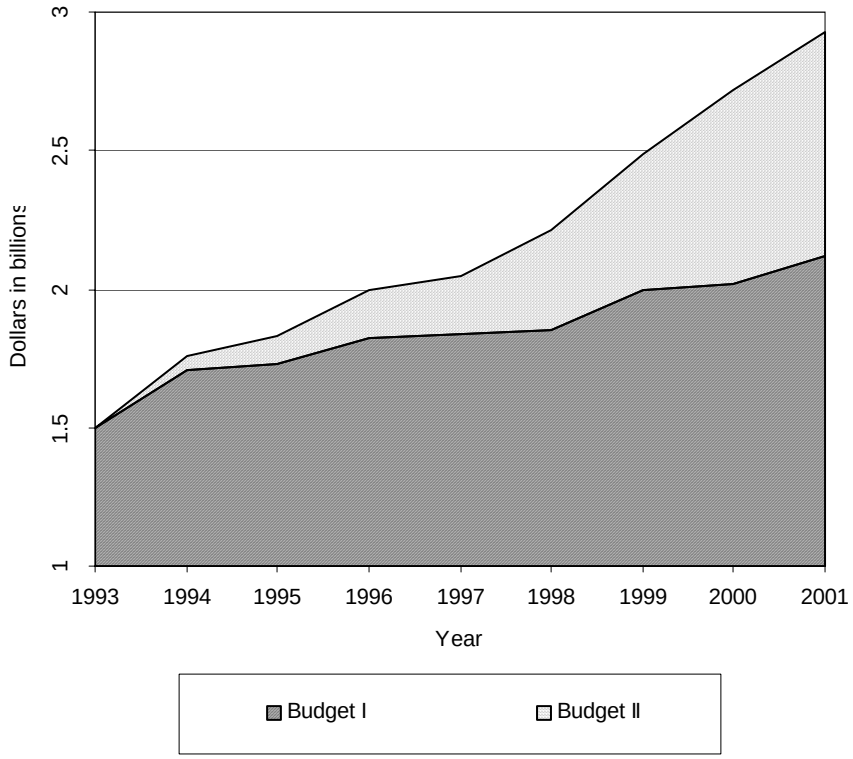
Only enhanced collection efforts have prevented a continuous decline since 1998.[55] The second graph, provided by the Northwest Portland Area Indian Health Board, illustrates the budget relative to inflation, without the benefit of collections.[56] The overall effect is that per capita spending power is roughly the same now as it was in 1991. In fact, accounting for 230,000 new users between 1991 and 2003, the buying power per user increased only 2 percent.[57]

[55] IHS increased collections by 453 percent from 1991 to 2003. *See* IHS, *Revenues and Buying Power Trends: Indian Health Service 2001–2003*.

[56] Northwest Portland Area Indian Health Board, *Creating Healthier Indian Communities for a Healthier America: Fiscal Year 2003 Indian Health Service, Tribal and Urban Needs-Based Budget*, June 13, 2001.

[57] IHS, *Revenues and Buying Power Trends: Indian Health Service 2001–2003*.

Figure 3: Comparison of Approved IHS Budget and IHS Inflation-Adjusted Budget



Source: Northwest Portland Area Indian Health Board, *Creating Healthier Indian Communities for a Healthier America: Fiscal Year 2003 Indian Health Service, Tribal and Urban Needs-Based Budget,* June 13, 2001.

Even in 1991, this fight against inflation and the resultant erosion of buying power was nothing new. The legislative history of the Indian Health Care Improvement Act reveals that Congress recognized that many factors prevented improvement of the health status of Native Americans, "not the least of which is the fact that rampant inflation is constantly eroding the purchasing power of the fiscal resources available to the IHS."[58]

These effects of inflation on financing for Native American health care are well documented, as Congress has repeatedly failed to provide funding sufficient to cover even the costs of inflation.[59] Yet, many public health programs could have received less funding than desired or needed over that same period. Consequently, it is important to examine these other health care programs, including Medicare, Medicaid, and federally funded health care for veterans, government employees, and prisoners.

[58] S. Rep. No. 94-1194, at 73 (1976), *reprinted in* 1976 U.S.C.C.A.N. 2711.

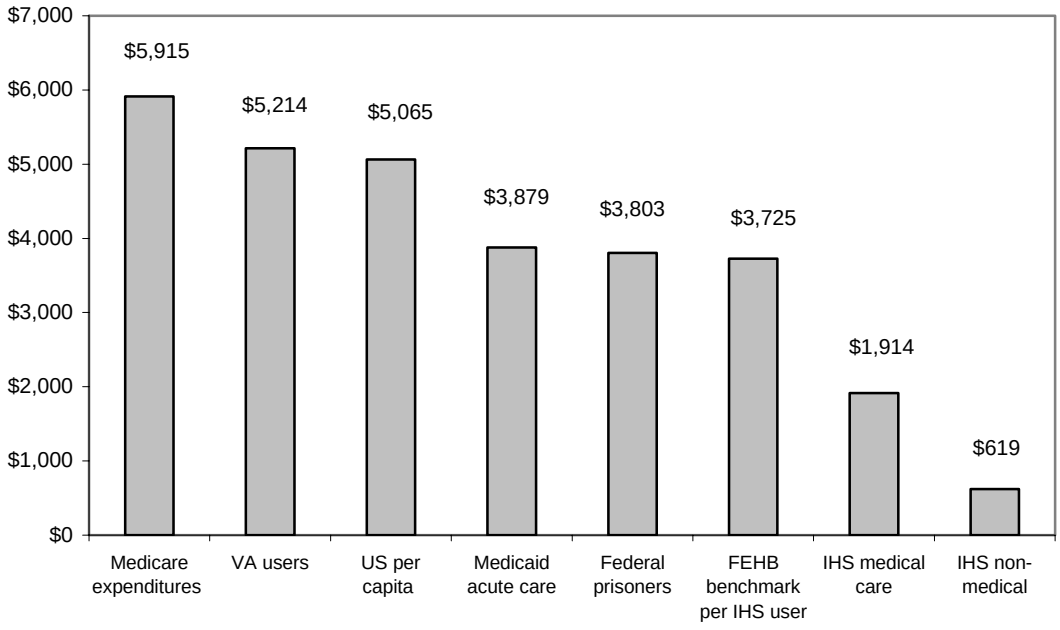
[59] Over the same period, the inflation adjusted discretionary outlays for all government programs increased 15.6 percent. *See* Robert C. Sahr, "Summary of National Government Budget Data," p. 10, <http://oregonstate.edu/ Dept/pol_sci/fac/sahr/sumbudg.pdf> (last accessed Mar. 29, 2004).

Comparison to Other Government Spending

Establishing that current funding levels are inadequate and that increased appropriations have failed to keep track with inflation does not necessarily complete the argument that federal policy discriminates against Native Americans. In a time of shrinking expenditures it is only natural that programs will experience cutbacks. It is helpful, then, to examine other federal programs to determine how their funding compares with that of Native Americans. Drawing this comparison leads to the conclusion that annual per capita expenditures for Native American health care programs fall below the level for every other federal medical program and standard. Comparisons available include federal prisoners, beneficiaries of Veterans Administration services, Medicare and Medicaid, and federal employees enrolled in the FEHBP.

Staking claim to the lowest level of federal funding is unfortunate enough standing alone. When the actual figures take form graphically, a simple comparison becomes a disturbing disparity. Figure 4 illustrates the importance placed on Native American health care relative to every other federal medical program.

Figure 4: Per Capita Health Care Expenditures



Source: U.S. Department of Health and Human Services, Indian Health Service, Office of Management Support, Division of Financial Management, "IHS Appropriations Per Capita Compared to Other Federal Health Expenditure Benchmarks," March 2003, submitted by fax Mar. 27, 2003.

In numerical terms, HHS estimates the FY 2003 annual per capita health care spending for the general population at $5,065. In contrast, IHS spent $1,914 per eligible user, or 38 percent of that spent by the general population.[60] Although updated figures are not yet available,

[60] U.S. Department of Health and Human Services, Indian Health Service, Office of Management Support, Division of Financial Management, *IHS Appropriations Per Capita Compared to Other Federal Health Expenditure Benchmarks*, March 2003, submitted by fax March 27, 2003.

the limited increases over the past two fiscal years have almost certainly lowered the amount spent on Native Americans relative to the general population—and every other federal program providing health care.

Rate of Increase Relative to Other HHS Components

The previous section compared funding for Native American health care in absolute terms with the funding for other health programs. In contrast, this section compares the increase in IHS funding with the increases for other HHS components, in particular the health-related components within CMS.

Comparing the FY 2004 rate of increase with other HHS programs, not surprisingly, IHS falls short. The 2.6 percent increase for FY 2004 compares with a 5.5 percent increase for Medicaid and a 10.9 percent for Medicare.[61] Over a longer period IHS fares no differently; it has the smallest rate of increase within HHS from FY 2000 to FY 2004.[62] Furthermore, when the annual IHS budget figures are adjusted for inflation it becomes apparent that the per capita spending power for IHS appropriations, in inflation-adjusted dollars, is roughly the same today as it was in 1991.[63] Looking at an extended period of time, the inflation-adjusted expenditures for HHS discretionary programs increased more than 300 percent from 1975 to 1999, compared with an increase of less than 200 percent for IHS programs for that same period. Notably, most of the divergence in annual increases for HHS and IHS programs has been created since 1990.[64]

Making this comparison between HHS and IHS programs creates a presumption that the congressional allocation of scarce discretionary funding reflects our nation's assignment of value to funding recipients. It could be said that requesting a different allocation of discretionary funds simply calls for an adjustment to the value assigned to the respective programs. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research offers guidance for assigning value in these situations. Its 1983 report suggests that the "priority in the use of public subsidies should be given to achieving equitable access for all before government resources are devoted to securing more care for people who already receive an adequate level."[65] Applying this guidance, it follows that demonstrating an ability to raise funding levels for other similarly situated programs, while refusing to raise levels for Native Americans, expands inequity and violates ethical principles. The extent of current inequities can either be attributed to intentional discrimination or gross negligence, especially when examined in light of other funding disparities and other actions taken contrary to the stated intent of decision-makers. One such statement of intent involves the apparent use of increasing third-party collections to offset the failure to raise appropriated funding levels.

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[61] HHS, *FY 2004 Budget in Brief.*

[62] NPAIHB, "FY 2004 IHS Budget Analysis," p. 39.

[63] U.S. Department of Health and Human Services, Indian Health Service, "10 Year Expenditure Trends," <http://www.ihs.gov/nonmedicalprograms/businessplan/Book1/IHS10YR.pdf> (last accessed October 21, 2004).

[64] National Congress of American Indians, "FY 2005 Appropriations: Indian Country and the Federal Budget," <http://www.ncai.org/main/pages/issues/other_issues/documents/Approps/2005_budget_recommendations.pdf> (last accessed Mar. 31, 2004).

[65] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Securing Access to Health Care, *The Ethical Implications of Differences in the Availability of Health Services*, vol. 1, March 1983, p. 5.

Improper Use of Increased Collections from Third Parties

When Congress made the IHS payor of last resort[66] and granted the IHS authority to collect payments from Medicare, Medicaid, and other public and private insurance programs, Congress anticipated that, as revenues increased from these third parties, there would be a tendency for Congress to offset those new revenue sources by withholding or limiting additional increases in appropriated funding levels.[67] Consequently, Congress included language to articulate the express intent that increased collections not be used to justify lower appropriations levels.[68]

Congress has failed to abide by this clear mandate. Only enhanced collection efforts have made up for shortfalls created by inflation and population growth, and prevented a continuous decline from 1991 until today.[69] Recall that collections from third parties increased 453 percent from 1991 to 2003.[70] As a result, Native American health care programs have come to rely on third-party providers for 16 percent of their funding.[71]

This pattern of reliance on third-party reimbursements has potential negative consequences beyond the replacement of needed appropriations, particularly in the face of shrinking state budgets. It is especially disturbing to the American Indian Health Commission for Washington State, where even slight changes in Medicaid benefits or eligibility would have serious consequences for tribal health care programs. According to the commission:

> Elimination of Medicaid adult dental benefits could jeopardize tribal dental programs that have taken years to build. The cost of establishing dental programs in rural areas, including the recruitment and retention of qualified dentists with the cultural competency to work in a Tribal setting has been significant. If the Medicaid revenue that sustains these programs is cut, entire communities may lose the capacity to sustain local dental services.[72]

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[66] The payor of last resort is entitled to seek payment or reimbursement after medical services are provided to a patient enrolled in other "third party" programs. These third-party programs include Medicare, Medicaid, CHIP, and private health insurance programs, among others. *See* 42 C.F.R. § 136.61 (2003).

[67] *See* 25 U.S.C. § 1641(a) (1994).

> Determination of appropriations. Any payments received by a hospital or skilled nursing facility of the Service (whether operated by the Service or by an Indian tribe or tribal organization pursuant to a contract under the Indian Self-Determination Act (25 U.S.C. §§ 450f *et seq.*)) for services provided to Indians eligible for benefits under title XVIII of the Social Security Act (42 U.S.C. §§ 1395 *et seq.*) shall not be considered in determining appropriations for health care and services to Indians.

Id.

[68] S. Rep. No. 94-1194, at 108 (1976), *reprinted in* 1976 U.S.C.C.A.N. 2746. "It is the intent of the Committee that any Medicare and Medicaid funds received by the Indian Health Service program be used to supplement—and not supplant—current IHS appropriations." Ibid.

[69] IHS, *Revenues and Buying Power Trends: Indian Health Service 2001–2003*.

[70] Ibid.

[71] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-2.

[72] American Indian Health Commission for Washington State, "Uniform Benefits Package for American Indians and Alaska Natives," position paper, Dec. 12, 2002, <http://www.aihc-wa.org/Issues/Documents/Position_Papers/Uniform_Benefits.pdf> (last accessed Aug. 27, 2003).

The impact would expand well beyond dental services. Some tribes rely extensively on third-party reimbursements to support their programs. For example, the Lower Elwha Band of Klallam of Port Angeles, Washington, has been so successful at enrolling all eligible patients that 95.4 percent of clinic users have a third-party source for health care coverage.[73] Any reduction in benefits from third parties causes an immediate reduction in money available to purchase health care services for the Lower Elwha Band specifically, and Native Americans in general.

IHS has raising collections to an even greater level as one of its long-term goals. As collections are raised more money is available to purchase additional services for facilities where funding is the single most limiting factor. To exactly what level collections could potentially rise is a disturbing unknown. Officials of the IHS estimate that at most collections could be increased 25 percent, but that estimate is conservative since the current infrastructure could not support an immediate 25 percent increase in services.[74] In general terms, any increase in services would require expanding overcrowded facilities and hiring additional staff in locations already unable to reach full staffing levels.[75] From the CMS perspective, it is impossible to precisely determine current CMS expenditures with current data collection systems.[76] Two factors contribute to that reality. First, the self-governance agreements make tribal services reporting to IHS voluntary. Current collections figures are based on voluntary reports and estimates. Second, for CMS services provided outside IHS facilities, inclusion in collection figures is dependent on self-reporting by the Native American patient.

Regardless of the level to which IHS is able to raise third-party reimbursements, the entire system's reliance on any third-party funds recovered will be real and substantial. Furthermore, even though congressional intent in assigning appropriations is difficult to surmise, the consistent widening of the gap between program-level funding and budget authority—and the resulting plateau in spending power—creates a strong presumption that third-party collections are being used to justify lower levels of appropriated funding. Congressional assignment of appropriations over the past 14 years has failed Native Americans and is further evidence of the intent to continue de-prioritizing the health care needs of Native Americans.

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[73] American Indian Health Commission of Washington State, "2003 American Indian Health Care Delivery Plan," p. 103, <http://www.aihc-wa.org/Issues/AIHCDP.htm> (last accessed Aug. 28, 2003).

[74] Interview with IHS executive staff, July 21, 2003. The IHS executive staff members who were present at this interview included Michel Lincoln, deputy director, Office of the Director; Duane Jeanotte, director, Headquarters Operations, Office of the Director; Robert McSwain, director, Office of Management Support; Gary Hartz, acting director, Office of Public Health; Paula K. Williams, director, Office of Tribal Self-Governance; Craig Vanderwagen, M.D., acting chief medical officer, Office of the Director; Michael Mahsetky, director, Legislative Affairs, Office of the Director; Lovell Hopper, director, Division of Financial Management, Office of Management Support; Cliff Wiggins, senior operations research analyst, Office of the Director; Jon Perez, Ph.D., director, Division of Behavioral Health, Office of Clinical and Preventive Services, Office of Public Health; Ron Demaray, division director, Self Determination, Office of Tribal Programs, Office of the Director; and Kitty Marx, senior policy analyst, Legislative Affairs, Division of Regulatory & Legal Affairs, Office of Management.

[75] Problems associated with overcrowded and aging facilities and the inability of IHS facilities to retain adequate staffing levels are discussed in detail in Chapter 3.

[76] Dorothy Dupree, Centers for Medicare & Medicaid Services, telephone interview, June 30, 2003.

Specific Funding Needs

Every tribal leader contacted, and every health care advocate interviewed, identified increased funding as an important aspect of any effort to improve health care for Native Americans. Obtaining additional funding, however, will not be simple. Thus, it is important to understand the specific impact of failing to provide adequate funding, as well as the influence of marginal funding gains. Tribal leaders have compiled these data, and have calculated the impact of incremental changes in funding. For every $100 million variation from requested funding levels, IHS, tribal, and urban health programs would gain or lose:

- 365,000 outpatient visits.
- 13,000 inpatient days.
- 115,000 dental services.
- 10,000 mental health contacts.
- 28,000 alcohol treatment visits.
- 23,000 contract health services outpatient visits.
- 16,000 public health nursing visits.
- 29,000 health education services.[77]

These figures are dramatic; they illustrate that with a $100 million, or 3.1 percent, increase in appropriated funding, the Native American health care system would be able to provide a considerable increase in services. Even an increase of $100 million, however, is still insufficient to compensate for the chronic under-funding of IHS and its estimated $3 billion annual funding shortfall.

In addition to identifying the specific benefits achievable for an unrestricted increase in appropriations, Native American health care advocates have identified specific funding deficiencies in the FY 2004 budget. The identified requests having gone unanswered, the shortfalls remain for FY 2005. The most dramatic shortfalls involve contract health services, contract support costs, and Urban Indian Health Programs. They will be discussed in sequence below.

Funding for Contract Health Services

The Contract Health Services (CHS) program has very specific funding problems and its persistent underfunding has had a haunting effect on Native Americans. As discussed in Chapter 3, the current program postpones, and in some cases denies outright, necessary medical services. Furthermore, the purchasing power of CHS funds continues to decline as the costs of service go up while the numbers of services IHS can provide go down.[78] If immediate increases are not provided, most tribes will fall into Priority I category—where the only procedures provided are

[77] NPAIHB, "FY 2004 IHS Budget Analysis."

[78] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-76. See this chapter's discussion of inflation for additional figures on general losses in service despite increasing funding levels.

those that save life and limb—several months earlier than spring as in recent years.[79] For the Cherokee Nation, in FY 2004, two-thirds of CHS funds had been spent by March 2004, with six months remaining in the fiscal year.[80] In addition, as of March 1, 2004, 3,394 cases had been deferred, equal to the number deferred in all of FY 2003.[81] These numbers do not include the requests that were not even made, knowing with certainty that they would be denied.

The FY 2005 budget request includes $497 million for contract health services, an $18 million, or 3.8 percent, increase over FY 2004. This represents a shortfall of more than $500 million relative to estimated need, and is well below the $60 million necessary to even maintain the current level of services.[82] Among all IHS programs, CHS is the most vulnerable to inflationary pressures.[83] It is estimated that between FY 1992 and FY 2003, CHS lost more than $250 million to inflation alone.[84] The following statistics illustrate the impact of recent inflation on the CHS program:

- From FY 1998 to FY 2003, billed costs per admission increased 38 percent from $10,903 to $15,065.
- During that same time, CHS inpatient admissions increased only 8 percent from 16,124 to 17,513.
- From FY 1998 to FY 2003, billed costs per visit increased 69 percent from $363 to $614.
- During that same time, CHS outpatient care declined by 38 percent from 208,802 to 128,571.[85]

Consequently, despite annual increases in CHS funding, totaling 27 percent from FY 1998 to FY 2003, the number of patient services provided has actually decreased.

On a positive note, the recently enacted Medicare Prescription Drug Improvement and Modernization Act[86] will increase the buying power of CHS funding by $8 million, allowing the purchase of 35,000 additional outpatient visits or 3,000 additional days of inpatient care.[87]

Nevertheless, the fact remains that, at current deteriorating levels, only treatment for life-threatening conditions will be funded, particularly toward the end of the fiscal year. Failure to immediately increase funding for CHS will lead to ever-increasing delays in delivering necessary, though not life-threatening, medical services.

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[79] NPAIHB, "FY 2005 Budget Analysis," p. 28.

[80] USCCR meeting with representatives of Cherokee Nation, Mar. 23, 2004.

[81] Cherokee Nation Health Services, "Contract Health Services Worksheet" (presented to USCCR at Cherokee Nation meeting March 23, 2004).

[82] *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Julia Davis-Wheeler, chair, National Indian Health Board). *See also* HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-2.

[83] NPAIHB, "FY 2004 IHS Budget Analysis," p. 22.

[84] Ibid.

[85] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-77.

[86] Medicare Prescription Drug Improvement and Modernization Act of 2003, Pub. L. No. 108-173, 117 Stat. 2066 (2003).

[87] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-77.

Funding for Contract Support Costs

As explained in Chapter 3, individual tribes and tribal consortia have been compacting and contracting with IHS under the Indian Self-Determination and Education Assistance Act to provide for their own health services.[88] In fact, compacting and contracting tribes (638 programs) now operate programs consuming more than 50 percent of IHS operating funds.[89] Perhaps the strongest point of contention for the tribes participating in tribal self-governance programs is the issue of contract support costs (CSC), specifically, the growing CSC shortfall. In testimony before the House Committee on Resources, the IHS deputy director, Michel Lincoln, provided the following definition of contract support costs:

> Contract support costs are defined under the Act as an amount for the reasonable costs for those activities that must be conducted by a tribal contractor to ensure compliance with the terms of the contract and prudent management. They include costs that either the Secretary never incurred in her direct operation of the program or are normally provided by the Secretary in support of the program from resources other than those under contract. It is important to understand that, by definition, funding for contract support costs is not already included in the program amounts contracted by tribes. The Act directs that funding for contract support costs be *added to* the contracted program to provide for administrative and related functions necessary to support the operation of the health program under contract.[90]

The National Congress of American Indians estimates the FY 2004 shortfall at $93 million; the FY 2005 shortfall will grow to $111 million under projected appropriations.[91] In FY 2003, Congress appropriated $285 million to meet 81 percent of the $350 million negotiated CSC level.[92] Although on average the tribes received 81 percent of CSC, many tribes received far less. In FY 2002, there were 14 tribes funded below 60 percent, with the lowest funded tribe receiving only 31.6 percent.[93] This disparity exists despite express wording in the Indian Self-

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[88] Indian Self-Determination and Education Assistance Act of 1975, Pub. L. No. 93-638, 88 Stat. 2203 (codified as amended in scattered sections of 25 U.S.C.). Under this law, tribes can contract with the federal government to take over the management of all or part of their health care programs; subsequent amendments allowed tribes to compact with the federal government to obtain more power and independence in the management of their health programs. In 1992, the Self-Determination Act was reauthorized through amendments to IHCIA. *See* Indian Self-Determination Act of 1992, Pub. L. No. 102-573, Title VIII §813(a), 106 Stat. 4590 (codified as amended in scattered sections of 25 U.S.C.).

[89] *Tribal Contract Support Cost Amendments of 2004: Hearing on S. 2172 before the Senate Comm. on Indian Affairs*, 108th Cong. (2004) (testimony of Dr. Charles W. Grim, director, IHS).

[90] *Contract Support Costs Within the Annual Indian Health Service Budget: Hearing before the House Resources Comm.*, 106th Cong. (1999) (testimony of Michel Lincoln, deputy director, IHS), <http://www.hhs.gov/asl/testify/t990224c.html> (last accessed June 1, 2004).

[91] *Tribal Contract Support Cost Amendments of 2004: Hearing on S. 2172 before the Senate Comm. on Indian Affairs*, 108th Cong. (2004) (testimony of W. Ron Allen, treasurer of NCAI). It is important to note that the negotiated contract support costs "are set by the government itself, through the negotiated and audited 'indirect cost rate' process established under OMB circular A-87." *See Tribal Contract Support Cost Amendments of 2004: Hearing on S. 2172 before the Senate Comm. on Indian Affairs*, 108th Cong. (2004) (testimony of Lloyd B. Miller, Sonosky, Chambers, Sachse, Miler & Munson, LLP).

[92] *Tribal Contract Support Cost Amendments of 2004: Hearing on S. 2172 before the Senate Comm. on Indian Affairs*, 108th Cong. (2004) (testimony of Dr. Charles W. Grim, director, IHS).

[93] IHS, "Tribal Leader Letter of February 18, 2004," p. 4, <http://www.ihs.gov/NonMedicalPrograms/otp/files/CSC_Draft_Circular_2004_xx.pdf> (last accessed June 1, 2004). To obtain an average near 80 percent, the above

Determination and Education Assistance Act that contract support costs shall be awarded. Currently, both the legislative and judicial branches of government are making efforts to resolve this issue. In the legislative branch, bills have been introduced in the House and Senate that would provide for the permanent and full funding of contract support costs. This legislation is discussed in detail in Chapter 5. In the judicial branch, the Cherokee Nation has filed suit to enforce the mandate of the act. The case awaits oral argument before the U.S. Supreme Court. A description of the case posture follows.

Two cases involving the same contractual dispute between the Cherokee Nation and the HHS have had certiorari granted before the U.S. Supreme Court.[94] The dispute centers on the wording of the Indian Self-Determination and Education Assistance Act, the Indian Self-Determination Amendments of 1988, and the contracts made pursuant to those statutes. Essentially, the tribes argue that the federal government has breached its contracts by failing to fully fund contract support costs.[95] The government argues in turn, that, by statute, funding is subject to the availability of appropriations and that contract support costs cannot be fully funded without reducing funding available to other tribes, in violation of statute.[96] In upholding the findings of the Department of the Interior Board of Contract Appeals, the Federal Circuit concluded that funds were available and that the government had breached its contracts with the tribes in not reimbursing all contract support costs.[97] The key ruling was that "there was no statutory restriction on reprogramming authority," thereby making funds available from the lump sum appropriation.[98] In contrast, the Tenth Circuit found that the specification of a set figure for contract support costs in the relevant appropriations bill illustrates that "Congress intended to limit the amount available for . . . contract support costs."[99] Consequently, the Supreme Court will resolve the contradictory opinions and decide whether the current tribal self-governance agreements are sufficient to mandate complete funding of contract support costs or whether future legislation would be required for such a mandate. Whether or not additional legislation is necessary, one current proposal has been presented and is discussed in Chapter 5.

Funding for Urban Programs

Urban funding has a unique set of problems. In addition to funding levels far below that of reservation Indians, urban Indians face representation problems that, among other factors, restrict how money can be spent on Urban Indian Health Programs.

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numbers are averaged with 166 tribes funded at 90 percent or greater, including 53 tribes funded at 100 percent or more. Ibid.

[94] Cherokee Nation of Oklahoma v. Thompson, 2004 U.S. LEXIS 2027 (U.S., Mar. 22, 2004) an appeal from Cherokee Nation of Oklahoma; Shoshone-Paiute Tribes of the Duck Valley Reservation v. Tommy G. Thompson; Michael J. Trujillo, 311 F.3d 1054 (10th Cir. 2002) and Thompson v. Cherokee Nation of Oklahoma, 2004 U.S. LEXIS 2028 (U.S., Mar. 22, 2004) an appeal from In re Cherokee Nation of Oklahoma, 2001 IBCA LEXIS 4 (I.B.C.A., Mar. 21, 2001).

[95] 334 F.3d at 1079.

[96] *Id.*

[97] *Id.* at 1095.

[98] *Id.* at 1086.

[99] *Id.* at 1065.

By some estimates, 61 percent of Native Americans live in urban areas.[100] The total amount requested for appropriation in FY 2005 for all urban Indian programs, treating 61 percent of all Native Americans, is $32.4 million, an increase of $791,000 from FY 2004. This represents approximately 1 percent of annual IHS appropriations for programs actually serving only 24 percent of the entire Native American population, or those fortunate enough to live in those areas with an urban Indian program. The other 37 percent of all Native Americans live in urban areas without urban Indian programs and have no IHS care whatsoever. Considering the total urban Indian population, the level for current unmet needs rises to more than $1.5 billion.[101] Nevertheless, advocates for urban health care request only an additional $6 million in the face of two compelling realities.[102]

First, and perhaps most importantly, the current political and fiscal climate is unlikely to support substantial increases in funding levels. Congress has shown no inclination to raise funding levels even enough to compensate for inflation, much less to immediately double or triple a multibillion-dollar program. Second, and almost overshadowed by the first concern, the current IHS structure, most notably facilities and employees, cannot accommodate immediate full funding.[103] Any attempt to fully fund urban Indian health care would require extensive structural change and a gradual increase in funding.[104] Certainly few, if any, Native American leaders would refuse an immediate and substantial increase in funding. The fundamental point is that, in the unlikely event that Congress appropriates $18 billion for IHS in FY 2005, it would still take several years before the system would be functioning at the expected level.

Restrictions on Funding

Failing to raise appropriations to an adequate level is the obvious way in which Native Americans are deprived of necessary funds, but it is not the only way. Federal rules and regulations governing how money is allocated and spent can also contribute to underfunding or an irrational distribution of funds. The most controversial of these and, as mentioned earlier, perhaps the most misunderstood, is entitlement status. To the tribes located in regions with significantly lower per capita spending by the IHS, how funding increases are distributed can be no less important. Finally, to those urban Indians who have lost funds designated for their use via regulations granting discretionary authority to tribal programs, appropriations regulations hold particular interest. Each consideration is discussed below.

[100] Urban Indian Health Institute, "National Aggregate Urban Indian Data," <http://www.uihi.org/data.asp> (last accessed Aug. 23, 2003).

[101] *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Kay Culbertson, executive director, Denver Indian Health and Family Services).

[102] Ibid.

[103] Ibid. *See also* Jeanotte interview.

[104] *The President's FY 2004 Budget for Indian Programs: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Kay Culbertson, executive director, Denver Indian Health and Family Services); ITU Budget Workgroup, "FY 2003 Needs Based Budget Presentation," p. 18, <http://www.npaihb.org/index.html> (last accessed Aug. 19, 2003).

Entitlement Status

The first of the issues surrounding federal rules and regulations with a potential impact on health services is the status accorded to the entire program in the appropriations process. The status of the program determines whether funding will be provided at levels defined by Congress on an annual basis (discretionary appropriations) or whether funding will be provided to cover actual need (entitlement programs).

Independent of these government labels, a perception has been created among Native American peoples over the years that health care is an entitlement for Native Americans. In simple terms, many Native Americans believe that they bargained for health care when they signed treaties giving up their land. Therefore, whether the government should finance the IHS is not the question; annual appropriations decisions should not be subject to congressional discretion. When the federal government accepted the responsibility, it became an "entitlement" for Native American peoples.

From the federal government perspective, the argument against entitlement status is obvious: granting that status would be prohibitively expensive.[105] As an entitlement similar to Medicaid, care would be provided, if necessary, and the government would be responsible for payment, subject to certain limitations. Passing legislation to formally transform Native American health care into a Medicaid-like entitlement would appear to be completely untenable. In the current fiscal environment, advocates must lobby unceasingly merely to obtain increases to keep pace with inflation.

From a Native American perspective, the entitlement question is not answered so simply. The individual Native American is unconcerned with the cost to the federal government. That the contract has already been acted upon ends the discussion. Some advocates for Native Americans, though, hesitate to embrace entitlement for both political and policy reasons.[106]

Politically, calling for entitlement status may act as a "poison pill" if pursued as part of the Indian Health Care Improvement Act.[107] It may be such a contentious issue that its inclusion would delay passage and foster opposition to other provisions that would have otherwise passed. Even if passed, its controversy may lead to a limitation on services or the attachment of unacceptable eligibility criteria.[108] Some programs, currently operating at an above average level, might be compressed to an average or minimum level.[109] Myra Munson, an attorney and advocate for Native American health care, expressed concern that granting entitlement status would become a ceiling or maximum on health care, as opposed to the floor envisioned by most entitlement advocates.[110] In addition, Native Americans would likely lose many of the public health benefits of the current system, including the many beneficial aspects of using IHS as a

[105] By some estimates per capita expenditures would more than double and the number of Native Americans eligible would increase dramatically. *See* Northwest Portland Area Indian Health Board, "Should Indian Health Care Improvement Act Propose Entitlement Status?" p. 6 (presented August 31, 1999 in Salt Lake City, UT).

[106] Ibid.

[107] Ibid., p. 2.

[108] Ibid., p. 5.

[109] Ibid., p. 6.

[110] Munson interview.

resource and advocate, and the flexibility to tailor services to local needs.[111] A closely related concern is that making health care an entitlement and forcing Native Americans to access mainstream health care systems would become a shrouded attempt to resurrect the failed assimilation policies of the past.[112]

With all these concerns, the Native American communities, collectively, have been unable to build a consensus on the definition and application of any potential entitlement program. What remains clear, though, is that the placement of Native American health care funding in the "lower" status of a discretionary expenditure makes a political statement that less value is given to Native Americans relative to other recipients of federal health care financing. Accordingly, it provides additional support to the argument that the federal government intentionally discriminates against Native Americans in the provision of health care.

To some extent, this debate is a fundamental debate over the true scope of the federal responsibility for providing health care to Native Americans—and whether that responsibility includes providing the necessary funding. Without a doubt, if Native American health care continues to be underfunded, quality will suffer. As long as funding remains subject to annual appropriations, then Congress has the option of whether or not to provide adequate care. With history as a guide, the Commission anticipates that underfunding will remain a perpetual obstacle to raising the health status of Native Americans. After Native American health care becomes an entitlement, the federal responsibility becomes a mandate, and funding will no longer be the single greatest limiting factor on raising the health status of Native Americans. For that reason, the question of entitlement status deserves recognition as an issue of immediate concern.

IHCIF Distribution Rules

Current distribution is determined by a combination of past funding levels and a distribution formula based on the level of current unmet need as explained earlier in the chapter. To the extent that funding levels represent ability to provide adequate care, uneven funding distribution creates inequity. This section will explain how current inequities are reinforced by the established distribution mechanism and its reliance on past funding levels.

According to the IHS Funding Distribution Worksheet, FY 2001 per capita spending levels varied from as little as $719 in the Oklahoma Area to as high as $1,415 in the Billings Area.[113] The national per capita average is $1,190. The Cherokee Nation has calculated the amount necessary to eliminate this disparity and to raise all IHS and tribal programs to 80 percent of needed funding. For FY 2001, its figure was more than $1 billion.[114] To address this

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[111] Northwest Portland Area Indian Health Board, "Should Indian Health Care Improvement Act Propose Entitlement Status?" p. 9 (presented August 31, 1999 in Salt Lake City, UT).

[112] Fox Testimony, Briefing Transcript, p. 188. Furthermore, this desire to assimilate is motivated by a "deep seated ambivalence about Indian people and Indian tribes. Assimilation is the ugly goal of many reforms that like the groundhog on 'Groundhog Day' reoccurs on a daily basis. It's seldom spoken, but it is often behind many reforms." Ibid.

[113] U.S. Department of Health and Human Services, Indian Health Service, *IHS Funding Distribution Area Per Capita Worksheet, FY 2001*. At $2,248, per capita spending in Alaska is actually the highest, but because of unique circumstances (including travel requirements and expenses) Alaska is excluded from this discussion.

[114] Ibid.

need Congress appropriated $26 million in FY 2003.[115] For the Oklahoma Area this marginal distribution amounted to $9.5 million to spend on approximately 300,000 IHS users.[116] At the current rate, funding for Oklahoma would have difficulty maintaining current levels, much less reaching the 80 percent threshold.

Administration of Specific Appropriations

Specific regulations govern the manner in which designated appropriations are spent. This section will explain how some regulations prevent efficient and effective administration of government funds. Two examples were presented during the October briefing.

First, Gallup Indian Medical Center officials explained how even minor facilities modifications were not permissible at the local level unless specifically authorized by Congress. The director of the facility explained one change that would have improved service, but lamented that the change would take years to go through the approval and appropriations process. In a similar situation, the Navajo Nation had been appropriated funds for the provision of substance abuse–related services. The IHS interpretation allowed the money to be spent on the construction of modular facilities, but would not allow permanent structures.[117] A typical solution to this problem entails drafting legislation, or amendments to legislation, including the specific land or facility modifications.[118] Depending on the vagaries of the legislative process, this might take years and, in some cases, be overcome by events prior to enactment. A related complaint by administrators of the Gallup center addressed the 18–24 month IHS process of negotiating lease agreements for facilities.[119]

A separate issue, identified by Norman Ration of the National Indian Youth Council, involved specific appropriations designated for an Albuquerque dental facility. One half of this funding was administered through nearby tribes who, in turn, used the funds elsewhere. The remaining half could only be spent through Title V, IHCIA program authorizing expenditures for urban Indian programs. Consequently, instead of going to the Sipi Dental Clinic, as intended by those who advocated for the appropriation, this funding went to the Albuquerque urban Indian facility, where it was spent in accordance with that facility's discretion. The funding indeed went to urban Indians, but not where intended.[120] Fundamentally, this is a representation problem. Urban Indians, though a majority, are primarily represented by the minority—specifically, the tribal leaders for that minority.

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[115] U.S. Department of Health and Human Services, Indian Health Service, "FY 2003 IHCIF Area Summary," <http://www.ihs.gov/NonMedicalPrograms/Lnf/2003/ AreaAllowanceSummary.pdf> (last accessed Apr. 6, 2004).

[116] Ibid.

[117] Bill Donovan, "Feds Seek 2.5 Million; Misspent Money Raises Complicated Options For Repayment or After-the-Fact Congressional Action," *Navajo Times*, vol. XXXXII, no. 20, May 15, 2003, p. 1.

[118] *See Regarding the 2005 Department of Interior Appropriations Bill: Hearing before the House Committee on Appropriations*, 108th Cong. (2004) (Testimony of Chad Smith, principal chief, Cherokee Nation), where the Cherokee Nation requested language authorizing a land purchase.

[119] Floyd Thompson, chief executive officer, Gallup Indian Medical Center, telephone interview, Apr. 20, 2004.

[120] Norman Ration, Nation Indian Youth Council, telephone interview, Apr. 15, 2004.

Role of Health Insurance in Providing Access to Health Care

Native American enrollment figures for job-based insurance and public insurance through Medicare and Medicaid programs fall well below those for white Americans. Consequently, fewer Native Americans are able to afford the health care they need and are forced to rely on IHS, seek out charitable care, or delay necessary treatment.[121] Data from the Kaiser Commission on Medicaid and the uninsured indicate that 49 percent of Native Americans have access to employer-sponsored health insurance, compared with 83 percent of white Americans.[122] For IHS users this figure was 22.9 percent in FY 2002 and 22.8 percent in FY 2003.[123] These low figures may be partly attributed to high unemployment among Native Americans (7.6 percent as opposed to 3.0 percent for white Americans in the FY 2000 census)[124] and partly to the fact that many jobs available to Native Americans do not offer health insurance.[125] In addition to those with job-based insurance, an estimated 17 percent of Native Americans (42 percent of IHS users) rely on public health insurance, such as Medicaid, Medicare, the State Children's Health Insurance Program (SCHIP), and the Veterans Administration services.[126] This leaves the remainder, more than a third of the Native American population (35 percent of IHS users), with

[121] Although comprehensive data on the charitable care provided to Native Americans is not available, if quantified it would certainly amount to a sizable percentage of annual spending on Native American health care. According to David Goehring, vice president of finance for the Rapid City Regional Health System, RCRH writes off $1.5 to 2 million per year in noncollectible debt from Native Americans. *See* David Melmer, "Health Care—A State Issue," *Indian Country Today*, vol. 23, no. 26, Dec. 10, 2003, p. 1. Furthermore, the Kaiser Foundation estimates that, in Oklahoma, the state government and private medical providers absorb more than $400 million each year in unpaid medical expenses. *See* Ray Carter, "Oklahoma's American Indian Population Complicates Insurance Analysis," *Journal Record Legislative Report*, Feb. 24, 2004.

[122] Henry J. Kaiser Family Foundation, "American Indians and Alaska Natives: Health Coverage and Access to Care," February 2004, <http://www.kff.org/minorityhealth/loader.cfm?url=/commonspot/security/getfile.cfm &PageID=31131> (last accessed Mar. 26, 2003). *See also* Kaiser Commission on Medicaid and the Uninsured, "Key Facts," p. 12, June 2003, <http://www.kff.org/minority health/loader.cfm?url=/commonspot/security/getfile. cfm&PageID=14366> (last accessed Dec. 30, 2003) (hereafter cited as Kaiser, "Key Facts"). A general consensus has developed among self-governance tribal leaders that the 49 percent figure (from the Kaiser study) for job-based insurance was inexplicably high. Furthermore, the deterioration of economic conditions over the past two years and its disproportionate affect on Native Americans will have reduced this figure considerably. *See* USCCR Staff Director meeting with the Tribal Self-Governance Advisory Committee, Sept. 16, 2003. Duane Jeanotte explained that "the availability of insurance in the total Indian population is not known, but anecdotal information suggests that it's less than other groups." Jeanotte Testimony, Briefing Transcript, p. 199. For the IHS and tribal user population Mr. Jeanotte estimates that 60 percent has some type of third-party coverage. Ibid., p. 202. Actual numbers provided by IHS place that figure at 65 percent. *See* IHS, Interrogatory Response 12.

[123] IHS, Interrogatory Response 12.

[124] U.S. Census Bureau, "Employment Status 2000," *Census 2000 Brief*, p. 5, <http://www.census.gov/prod/2003 pubs/c2kbr-18.pdf> (last accessed Sept. 22, 2003).

[125] Kaiser, "Key Facts."

[126] By some estimates as many as 40 percent of Native Americans are eligible for Medicaid, with more eligible for Medicare and SCHIP, and as many as 50 percent have private insurance, yet IHS estimates that only 25 percent of the money spent on Native American health care comes from non-IHS sources. *See* Kaiser, "Key Facts." Veterans Administration programs serve more than 165,000 Native Americans. *See* "VA and HHS to Improve Health Care for Indian Veterans," *Seminole Tribune*, Mar. 21, 2003, p. 4. Additional sources include the TriCare program with the Department of Defense, serving 12,800 Native Americans and their families, *see* "Hopi Mom Among Missing," *Newsday*, Mar. 30, 2003, p. W18; and state and federal correctional institutions, serving almost 29,000 inmates, *see* Bureau of Justice Statistics, "American Indians and Crime," 1997, <http://www.ojp.usdoj.gov/bjs/pub/pdf/aic.pdf> (last accessed July 11, 2003).

no insurance at all, compared with 12 percent of the white population.[127] For those individuals, IHS is the only obligated provider. Significantly, just under half of low-income uninsured Native Americans report having access to IHS.[128] If IHS is unable to provide service, these uninsured Native Americans frequently go without health care until the situation requires emergency attention. Typically, "uninsurance is correlated with worse health outcomes, in part because of delayed diagnoses and fewer options for treatment."[129]

While not diminishing the importance of insurance, at least two commentators suggested that insurance coverage and health care access were not coterminous.[130] Equating the two terms suggests that the only solution necessary involves expanding insurance coverage when so many other factors affect Native American health care, as explained in chapters 2 and 3. Nevertheless, the fact remains that those with health insurance are more likely to receive quality health care than those without health insurance. With that in mind, the only rational explanation for the inordinately high number of uninsured Native Americans must be the presence of insurmountable barriers to obtaining health insurance. Following is a discussion of those barriers and the most effective ways to eliminate them. Barriers to obtaining insurance include the perception that health care is an entitlement, the stigma associated with public programs, confusing and difficult enrollment processes, widespread concern that participation will lead to the closure of IHS, and the current structure of public health insurance programs. Each will be discussed below.

A percentage of the uninsured are eligible for coverage, but are not enrolled, either because they are somehow prevented from enrolling or they choose not to enroll in programs available to them. One recent study found that "up to 78 percent of AI/AN [American Indian/Alaska Native] elders were eligible for, but not enrolled in one or more public programs."[131] Nevertheless, substantial data problems prevent validation of that study and defining any under-enrollment percentage across the entire Native American population.[132] Of those who are not yet enrolled, at least some choose not to enroll based on the belief that the federal government is required to provide health care, without regulation or limitation, as a result of treaties and obligations created in court decisions and legislation. Moreover, full

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[127] Henry J. Kaiser Family Foundation, "American Indians and Alaska Natives: Health Coverage and Access to Care," February 2004, <http://www.kff.org/minorityhealth/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=31131> (last accessed Mar. 26, 2003).

[128] Stephen Zuckerman et al., "Health Service Access, Use, and Insurance Coverage Among American Indians/Alaska Natives and Whites: What Role Does the Indian Health Service Play?" *American Journal of Public Health*, vol. 94, 2004, p. 57.

[129] Detailed Summary of the Health Care Equality and Accountability Act of 2003, provided by fax from the office of Rep. Donna Christensen, Oct. 23, 2003.

[130] Melissa Charlie, Navajo Nation, telephone interview, Apr. 30, 2004; Bill Elliott, health director, Fallon Paiute Shoshone Tribe, e-mail response to USCCR questions, May 14, 2004.

[131] Langwell, *Eligibility and Enrollment in Medicaid*, December 2003, p. 15.

[132] Ibid., pp. 1-3. These data issues, affecting estimates in 15 states with the highest Native American populations, resulted in a high degree of uncertainty and a low level of confidence in the separate estimates of AI/AN eligibility and AI/AN enrollment in Medicaid, SCHIP, and Medicare. This uncertainty rose to such a level that the project objectives were altered in favor of a less ambitious methodological study. Ibid., p. 1. Specific data issues included varying definitions of the AI/AN population; the use of different data sources over different time periods; and the use of different assumptions in the acquisition of available source data. Ibid., p. 24.

reimbursement should be neither costly nor burdensome for the individual patient.[133] Many Native Americans feel that when their ancestors entered into treaties that promised health care for Native Americans they did not bargain for the Medicare and Medicaid registration and enrollment procedures, nor their burdensome rules and regulations.[134] Likewise, they feel it is unnecessary to comply with the many restrictions accompanying the myriad rules and regulations.[135] This perception of burden derives from several factors, including requests for private information, the necessity for documentation to support the paperwork, and the repeated demands on their time and energy.[136] Additional factors include the historical basis for mistrusting federal programs, concerns regarding trust income, and the dynamic whereby grandparents provide childcare for grandchildren.[137] Some action has been taken at the state level to reduce the perceived burden. For example, tribal leaders in Montana have been lobbying for the simplification of the 17-page Medicaid form.[138] Some states have had success reducing the complexity of their forms; California now has a seven-page form, down from 27 pages.[139] The additional requirement that these forms be prepared every six months adds expense, creates aggravation, and effectively forms a barrier to health insurance for many Native Americans.[140]

Significantly, tribally operated facilities have proved to be more effective at increasing enrollment in and collecting from public insurance programs than federal IHS facilities.[141] This has been the case because Native Americans are typically more comfortable releasing private information to other Native Americans; the tribal facilities are motivated to seek additional funds available to them; the tribal facilities use a more flexible billing system capable of adapting to changing reimbursement requirements; and the tribal facilities experience less turnover, enabling the facility to build relationships with state government officials.[142] Furthermore, studies indicate that "one-to-one interaction and oral communication modes are critical to communicating information" to Native Americans.[143]

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[133] Dupree interview; Dupree Testimony, Briefing Transcript, p. 216. *See also* Langwell, *Eligibility and Enrollment in Medicaid*, pp. 8, 36.

[134] Langwell, *Eligibility and Enrollment in Medicaid*, p. 44.

[135] Dupree interview. *See also* Langwell, *Eligibility and Enrollment in Medicaid*, p. 8.

[136] A study by the California Policy Research Center found that the requirement for the production of *any* documents or records to determine eligibility was problematic. Delight E. Satter et al., "Improving Health Insurance Coverage for American Indian Children and Families under Healthy Families," *SCHIP Final Report*, June 2002, p. 15, <http://www.healthpolicy.ucla.edu/pubs/files/AIAN_report_062002.pdf> (last accessed July 14, 2003) (hereafter cited as Satter et al., "Improving Health Insurance Coverage"). *See also* Dupree interview; IHS, Interrogatory Response 8. *See also* Langwell, *Eligibility and Enrollment in Medicaid*, pp. 8, 9, 46. In many states it is not uncommon for patients to have difficulty obtaining birth or marriage certificates because they do not exist, or because it represents an additional expense.

[137] IHS, Interrogatory Response 8.

[138] "Tribal Leaders, Governor Discuss Economics," *Missoulian*, Oct. 11, 2003, p. B1.

[139] James Crouch, California Rural Indian Health Board, telephone interview, Apr. 28, 2004.

[140] Crouch interview. *See also* Charlie interview and Langwell, *Eligibility and Enrollment in Medicaid*, p. 9.

[141] Dupree interview. *See also* Chapter 3.

[142] Ibid.

[143] Langwell, *Eligibility and Enrollment in Medicaid*, p. 36.

In addition, Native Americans have low insurance participation rates because they fear that participating in public insurance programs could lead to the elimination of IHS.[144] This fear has been reinforced by budget proposals that have, in essence, used the amount collected from public insurance programs to demonstrate an increase in federal spending, without necessarily increasing appropriated funding levels, a dynamic that has guided budgetary policy over the past 10 or more years.[145]

The stigma sometimes associated with public programs also limits Native American enrollment in Medicare and Medicaid. Historically, stigma has centered on the perception others have of welfare recipients.[146] Many beneficiaries of public programs feel that they are perceived as lazy and undeserving, and fail to get respect as a result of their decision to accept public assistance.[147] A study by George Washington University researchers has found that the actual stigma is even broader.[148] Stigma is related as much to how recipients will be treated in the application process and how health care providers will treat those recipients once they are enrolled, as it is to public perception.[149] This stigma is amplified by several of the procedural factors discussed below.

Many Native Americans are hindered by the confusing and difficult nature of the enrollment process.[150] Very few Native Americans understand the Medicaid and SCHIP eligibility requirements; in fact, many IHS employees are equally confounded.[151] At least one state, Oklahoma, has solved this problem by placing state employees in Indian health facilities to facilitate Medicaid enrollment.[152] In other states, IHS and tribal officials encounter resistance working with county and state workers.[153] One frequent misunderstanding in the enrollment process involves Native Americans being asked for co-payments for programs such as SCHIP, when they are specifically exempt from the co-payment requirement.[154] Any form of cost sharing acts as a barrier to enrollment in public programs, more so when the co-payment is neither required nor necessary.[155] In addition, at least four states (California, Oregon, Washington, and Idaho) are debating co-payment and/or premium provisions to their state Medicaid programs.[156]

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[144] Satter, "Improving Health Insurance Coverage."

[145] Lovell Hopper, director, Division of Financial Management, Indian Health Service, interview in Rockville, MD, July 21, 2003. *See also* this chapter's discussion of the improper use of increased collections.

[146] Langwell, *Eligibility and Enrollment in Medicaid*, p. 37.

[147] Sara Rosenbaum et al., "Beyond Stigma: What Barriers Actually Affect the Decisions of Low-Income Families to Enroll in Medicaid?" July 2000, <http://www.gwu.edu/~chsrp/pdf/stig.pdf> (last accessed July 11, 2003).

[148] Ibid.

[149] Ibid.

[150] Dupree interview and Langwell, *Eligibility and Enrollment in Medicaid*, p. 8.

[151] Ibid. *See also* IHS Interrogatory Response 8 and Langwell, *Eligibility and Enrollment in Medicaid*, p. 37.

[152] Chris Walker, executive director, Cherokee Health Services, interview in Washington, DC, Apr. 23, 2004; Jim Farris, Hastings Indian Hospital, telephone interview, May 19, 2004; James Cussen, Claremore Indian Hospital, telephone interview, May 27, 2004; Thompson interview.

[153] IHS, Interrogatory Response 8.

[154] *See* Dupree Testimony, Briefing Transcript, p. 212, and Dupree interview.

[155] Dupree Testimony, Briefing Transcript, p. 212.

[156] Crouch interview. *See also* Northwest Portland Area Indian Health Board, *2004 Legislative Plan*, Feb. 11, 2004, p. 7.

In a very encouraging development, the state of Washington attempted to implement a special provision to allow a waiver of co-payments for Native Americans. However, the Centers for Medicare & Medicaid Services (CMS) recently notified Washington that doing so violated Title VI of the Civil Rights Act.[157] Another historical error has been the application of liens to enforce payment of medical bills. Many Native Americans in northern Nevada, and elsewhere, refuse to apply for Medicaid for fear they will lose their property.[158] Compounding the overall lack of knowledge is inconsistent guidance provided by CMS. Because CMS regulations are seen as unclear and incomplete with respect to Native American health care—since they are not aligned with IHS regulations and policy—CMS policy is frequently interpreted by telephone from CMS headquarters.[159] Therefore, the answer to a specific question, and consequently, policy at the local level, may depend on which CMS official answers the telephone on that specific occasion.[160]

Yet another solution to enrollment problems can be found in the Medicaid Administrative Match program. Under the program, tribes may contract with a state to perform outreach and educational activities.[161] A few states, including Washington, Oregon, Alaska, and Idaho, have granted these contracts to tribes.[162] Extending this program to other states requires the approval and coordination of each individual state. Federal encouragement may be necessary to accelerate this process.[163]

In addition to factors adversely affecting individual enrollment in insurance programs that limit access to health care, there are procedural factors that limit access to care. One such factor is the association of the 100 percent Federal Medical Assistance Percentage (FMAP) with the IHS facility, rather than the individual. In general terms, states may pay a portion of Medicaid costs, while the Federal Government also pays a portion of the costs (FMAP) based on a formula established by statute.[164]

Under the current arrangement, 100 percent federal reimbursement for state expenditures is dependent on Medicaid-eligible Native Americans receiving health services at approved IHS

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[157] Northwest Portland Area Indian Health Board, *2004 Legislative Plan*, Feb. 11, 2004, p. 7. The Northwest Portland Area Indian Health Board has joined the State of Washington and the American Indian Health Commission of Washington in challenging that determination.

[158] Alan Burgess, Tribal Health Administrator, Owyhee Community Health Facility, telephone interview, May 12, 2004. *See also Regarding the Reauthorization of the Indian Health Care Improvement Act H.R. 2440 and S. 556 Title IV and Amendments to the Social Security Acts: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Myra Munson, Sonosky, Chambers, Sachse, Miller & Munson, LLP), and Langwell, *Eligibility and Enrollment in Medicaid*, p. 43.

[159] Dupree interview. *See also* Department of Health and Human Services, Centers for Medicare and Medicaid Services, Response 6 to the Commission's request for Affected Agency Review, July 2004, (hereafter cited as CMS, AAR Response).

[160] Dupree interview; Fox interview. *See also* CMS, AAR Response 7.

[161] Northwest Portland Area Indian Health Board, *Tribal Implementation of Medicaid Administrative Match*, September 2003, p. 1. These activities include those performed by health care providers, as well as by administrative staff.

[162] Ibid.

[163] Ibid., p. 3, and Langwell, *Eligibility and Enrollment in Medicaid*, pp. 8–9.

[164] U.S. Department of Health and Human Services, "Office of Health Policy, Federal Medical Assistance Percentages," <http://aspe.os.dhhs.gov/health/fmap.htm> (last accessed Dec. 18, 2003).

and tribal facilities. Currently, non-IHS facility based services such as contracted health care, long-term care, and home care do not qualify for 100 percent FMAP reimbursement.[165] In the absence of full reimbursement by the federal government for health services provided to Native Americans enrolled in Medicaid, states are required to pay a portion of the costs of health services received at non-IHS approved facilities. Consequently, states have no financial incentive to increase Native American enrollment in Medicaid. By extending the 100 percent FMAP to all facilities, an incentive is provided to the states and they will be more likely to encourage Native American enrollment in public programs.

A slightly different manifestation of this same issue is raised in the context of tribal nursing homes. Because tribal nursing homes are not eligible for 100 percent federal reimbursement, states are less inclined to grant state certification.[166] Uncertified facilities are ineligible for Medicare certification, making them unprofitable, particularly on or near reservations.[167] Other procedural barriers include the coverage available under Medicare Part B and various technical issues associated with those eligible for both Medicaid and Medicare, or dual eligibles.[168]

In addition to the system and facility requirements, individual eligibility requirements can also impose barriers. In the context of Medicare, the requirement for 40 quarters of Social Security–covered employment excludes many elderly applicants who would otherwise qualify for Medicare. With high unemployment rates on reservations and the disproportionately high number of persons failing to meet the 40-quarter requirement, tribes have sought a Native American exemption.[169] Such an exemption from the 40-quarter requirement would markedly increase Medicare eligibility. Furthermore, confusion and insufficient information about the

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[165] U.S. Department of Health and Human Services, Indian Health Service, "Speaking With One Voice IHS, Tribes, Urban" (Draft Report on the Indian Health Service Regional I/T/U Consultation Meeting held Feb. 1, 2, 1999, in Reno, Nevada) <http://www.ihs.gov/ AdminMngr Resources/reauthor/files/ihs-5ren.doc> (last accessed July 14, 2003) (hereafter cited as IHS, "Speaking With One Voice"). *See* Christian Richardson, "Federal Decision on Indian Health Care Reversed," *Aberdeen American News*, Oct. 4, 2003, p. A4. This may be expanding to include coverage of contracted services. On September 30, 2003, a federal judge in South Dakota (in an unpublished decision) ruled that the Centers for Medicare & Medicaid Services must reimburse the South Dakota Department of Social Services 100 percent of the costs of medical services provided under the CHS program for "essential" treatment. Ibid. *See also* Dupree Testimony, Briefing Transcript, p. 211.

[166] Dupree Testimony, Briefing Transcript, p. 224. It is important to recognize that this is an issue separate from Medicare certification. See CMS, AAR Response 9. To become certified, a long-term care facility must have a deficiency-free survey or, if there are deficiencies, a plan of correction. In addition, in many states the first requirement is a demonstration of need. *See* Cindy Myers, "Health Care Financing Administration, South Dakota State-Tribal Relations Committee Meeting Minutes," Aug. 30 and 31, 2000, <http://legis.state.sd.us/interim/2000/ minutes/MSTR0830.htm> (last accessed Mar. 26, 2004).

[167] Dupree Testimony, Briefing Transcript, p. 224.

[168] Ibid., pp. 213–14. During the October briefing, the CMS representative, Dorothy Dupree, identified an issue with dual eligibles as a barrier to reimbursement. A request to CMS for additional information was answered more than four months past the requested response date and only two days prior to final submission of this report. The CMS responded in that answer to interrogatories that it was unaware of any barriers constructed by dual eligibility. Reconciling the conflicting inputs from CMS representatives proves difficult in light of the CMS delay in responding to the interrogatory regarding the financial implications of billing Medicaid first in dual eligibility situations. *See* U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Response to the Commission's Interrogatory 8, June 2004 (hereafter cited as CMS, Interrogatory Response).

[169] Centers for Medicare & Medicaid Services, "Current Issues."

availability of Medicaid to purchase Medicare Part B coverage have excluded an additional undefined number of elderly Native Americans.[170] In many of these cases, "patients did not have access to Medicare advisors or were not fully informed of this option" and its benefits.[171] Consequently, IHS has pursued equitable relief in the form of special enrollment for potential Medicare beneficiaries in selected locations.[172] For those who have passed the age of enrollment, CMS applies a late fee. This prevents individuals from waiting until they are ill with costly health conditions before they enroll. Title II, Section 419(b)(2), of the Indian Health Care Improvement Act would waive the Medicare late enrollment penalty, as discussed in more detail in the next chapter.[173]

Relationship Between IHS Health Care and Third-Party Collections

Whether an individual Native American patient has some form of health insurance is irrelevant to his or her eligibility to receive IHS health care. The existence of health insurance only affects the ability of IHS to seek reimbursement. To the extent that IHS is reimbursed for the care it provides, every dollar gained, in theory, is one additional dollar available for health care for other Native Americans. For FY 2004, this increase in services is estimated to be almost $600 million, not including unreported tribal reimbursements.[174] Over the period 1993–2003 this recovery from third parties has exceeded $4 billion. Without reimbursement, IHS would still have provided many of the services for which IHS was reimbursed, but an additional $4 billion would be unavailable for IHS to use for providing services to other uninsured Native American patients.

As illustrated, IHS collections from third parties have increased dramatically in the past 10 years.[175] More specifically, FY 2003 third-party collections are three times greater than the amount collected in FY 1995.[176] This remarkable improvement in collections was achieved through higher negotiated Medicare and Medicaid rates; new authority to bill under the State Child Health Insurance Program; and more efficient business management practices that involve more comprehensive patient eligibility determination, improved encoding and documentation of

[170] Dupree interview.

[171] IHS, Interrogatory Response 12.

[172] IHS, Interrogatory Response 12. Under these agreements, beneficiaries able to demonstrate to SSA that erroneous advice was provided resulting in their non-enrollment are eligible for "equitable relief." *See* National Indian Health Board, Medicare/Medicaid Policy Committee, *Prioritizing Issues for CMS*, Jan. 6, 2003, edited Jan. 17, 2003 (sent by fax from Bob Newcombe, Alamo Navajo Health Center, May 4, 2004). This agreement is illustrative of the CMS attitude toward IHS and tribal programs. Where possible, "the funding authority under Medicare and Medicaid has been liberally construed to accommodate administrative limitations of IHS providers, and to accommodate the increasing operation of IHS funded health care activities by Indian tribes and tribal organizations." *See* CMS, AAR Response 3.

[173] *See* Chapter 5.

[174] HHS, *FY 2005 Indian Health Service Justification of Estimates for Appropriations Committees*, p. IHS-2.

[175] U.S. Department of Health and Human Services, Indian Health Service, "Indian Health Service FY 2004 Performance Plan, FY 2003 Revised Final Performance Plan and FY 2002 Performance Report," Sept. 13, 2002, p. 13, <http://www.ihs.gov/AdminMngrResources/Budget/ downloads/FY_2004/GPRA%20Perf-Plan%20Report.doc> (last accessed July 14, 2003).

[176] IHS, Interrogatory Response 30.

services, and improved claims processing.[177] Despite this significant improvement, barriers to full reimbursement remain; they include a lack of data on eligibility and enrollment, Medicaid reimbursement mechanisms favoring simplicity over higher reimbursement rates, inadequate training, flaws in the tracking and billing process within IHS, and a lack of leadership and motivation at the local level.

Forming an umbrella over each of the barriers affecting increased enrollment is the last of those listed above—the leadership provided to the individual operating units. More specifically, it is local unit and area leaders who must make the decisions as to how limited resources will be applied. As discussed earlier, when tribes or tribal organizations take over IHS programs, third-party collections inevitably increase dramatically.[178] Experts attribute the relative increase at least partially to motivation and creativity.[179] This is not to say that IHS facilities have been unable to increase collections. One notable example includes the Hastings Indian Hospital. Under the leadership of John Farris, Hastings has raised its third-party collections to the point where collections now exceed appropriations and 50 percent of patients now have some form of third-party insurance.[180] This has been achieved largely through the use of state representatives in the hospital in coordination with an increasing number of patient benefits coordinators.[181]

One noteworthy barrier to full collection is a lack of data.[182] As noted earlier, enrollment and eligibility data for public insurance programs are inaccurate and incomplete. With complete and accurate data IHS and tribal health programs could maximize enrollment, increase reimbursement from third parties and, in the end, provide more and higher quality health care to a larger number of patients. In addition, this accurate data on eligibility and enrollment would enable IHS, CMS, and the tribes themselves to redirect financial and administrative resources to where the need is greatest. For example, if a particular tribe were experiencing a particularly high level of infant mortality, that tribe could choose to emphasize prenatal care and education. If another tribe continued to struggle with diseases typically associated with poor sanitation practices, it could direct its resources into building appropriate sanitation facilities. With this

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[177] This improvement has required considerable investment in hardware/software development and the employment of additional staff for following up on aging accounts. *See* IHS, Interrogatory Response 30; ULP Workshop Brief, "Addressing Critical Concerns of Health Care Systems American Indians," <http://www.ahrq.gov/news/ulp/tribal/ulptribal10.htm> (last accessed Apr. 27, 2004); Indian Health Service, "Indian Health Service FY 2004 Performance Plan, FY 2003 Revised Final Performance Plan and FY 2002 Performance Report," Sept. 13, 2002, p. 13, <http://www.ihs.gov/AdminMngrResources/Budget/downloads/FY_2004/GPRA%20Perf-Plan%20Report.doc> (last accessed July 14, 2003).

[178] *See* earlier discussion in this chapter.

[179] Melanie Knight, Government Resources, Cherokee Nation, telephone interview, May 19, 2004.

[180] Knight interview; Farris interview. *See also* Langwell, *Eligibility and Enrollment in Medicaid*, p. 45. In a one year effort, the Hastings facility was able to demonstrate a 45 percent increase in enrollment in entitlement programs.

[181] Farris interview.

[182] Jeanotte Testimony, Briefing Transcript, p. 199. The use of the all-inclusive rate, described below, also leads to data problems. One reason to use the all-inclusive rate is the minimal data-keeping requirement. *See* Dupree Testimony, Briefing Transcript, pp. 211–14. In addition, throughout this report the Commission has identified problem areas where insufficient data was listed as a contributing factor. Although the technical details are beyond the scope of this report, it is obvious to the Commission that the data management system currently in use for tribal and IHS programs requires significant improvement.

ability to redirect resources, individual tribes could maximize the health care improvement for a fixed expense.

Medicaid and Medicare reimbursement mechanisms erect a second barrier to increased collections. A number of different reimbursement mechanisms are available for each program and for each different type of medical facility. Each has its own set of advantages and disadvantages, as explained below.

For IHS and tribal facilities, Medicaid reimbursement is based on "all-inclusive rates," calculated as either a per-day amount for all inpatient services provided on that day, or as an encounter rate for outpatient services.[183] The all-inclusive rates are coarsely developed averages, which may vary significantly from actual costs. This variance is problematic on its own, but whether an encounter is defined as a single contact with a health care provider or as a single day where one or more health care providers is seen can magnify the problem. Depending on the nature of the individual contacts with a health care provider and the amount that the actual cost differs from the all-inclusive rate, the reimbursement amount may be significantly more or less than the amount anticipated or due.[184] In general, the smaller facilities benefit using this methodology, whereas the larger facilities are more likely to benefit from an itemized model. In fact, a study by Medical Learning Inc. found that every one of the larger facilities surveyed would recover more under a full-cost recovery model than they would using the all-inclusive rate.[185] This problem is magnified by the delay in translating real-cost data to accepted reimbursement rates. For example, the FY 2002 Medicare/Medicaid reimbursement rates for IHS facilities were established using FY 2000 actual cost data for IHS.[186] Again, limited data prevent IHS and tribal health programs from accurately evaluating the losses attributed to this cost management system. The Office of Management and Budget recognized this problem as it expressed concern about the "quality and comprehensiveness" of IHS cost report data.[187] Despite potential negative effects of the averaging and time delay, effective negotiation by IHS has produced a very favorable reimbursement rate compared with past reimbursement rates, which

[183] For a partial explanation of the all-inclusive rate calculation, *see* Jeanotte Testimony, Briefing Transcript, p. 201 and Dupree Testimony, Briefing Transcript, p. 214. *See also Regarding the Reauthorization of the Indian Health Care Improvement Act H.R. 2440 and S. 556 Title IV and Amendments to the Social Security Acts: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Myra Munson, Sonosky, Chambers, Sachse, Miller & Munson, LLP). The all-inclusive rate is not expressly authorized by law. Instead, it is applied using CMS discretion by excepting IHS facilities from otherwise applicable payment policies in light of limitations in the IHS ability to track costs.

[184] Centers for Medicare & Medicaid Services, "Current Issues." *See also* IHS, "Speaking With One Voice," and Dupree Testimony, Briefing Transcript, pp. 215–16.

[185] Medical Learning, Inc., "IA-00-165 Inter-Agency Agreement between Indian Health Service (IHS) and Centers for Medicare and Medicaid Services (CMS)—Phase II: Recommendations for Systems Changes to Address Itemized Medicare Billing in IHS/Tribal 638 Facilities," Final Report, November 2002, p. 1 (hereafter cited as MLI, "IA-00-165").

[186] Barry Clendenin, "Medicare/Medicaid Payment Rates for IHS Facilities" (Office of Management and Budget Memorandum of Mar. 22, 2002). For calendar years 1998, 2000, 2001, 2002, and 2003 two-year-old data were employed. For calendar year 1999 the delay was three years; for calendar year 2003 at least some data was from FY 2002. *See* IHS and CMS, "IHS Cost Report Initiative: Introductory Briefing with History and Future Plans," Apr. 11, 2003.

[187] Ibid.

"has made a tremendous difference in helping" the tribes increase collections.[188] Another very important characteristic of the current system is that it has "made recovery possible for facilities that have lacked the capacity to do full individual cost reports and for whom satisfying the requirements of the new outpatient prospective payment system regulations would have been virtually impossible."[189]

For Medicare, different reimbursement mechanisms are used for inpatient and outpatient services.[190] For inpatient admissions, reimbursement is based on Diagnostic Related Groups (DRGs), using a common prospective payment system.[191] For outpatient facilities, reimbursement is based on costs; for outpatient professional services, reimbursement is based on the National Medicare Fee Scale (NFS). Both the DRG and NFS payment systems use cost averaging similar to the all-inclusive rate, but with a broader sampling base.[192] IHS has not calculated the loss due to averaging under either the NFS or DRG reimbursement methodologies, nor under the cost-based system used for nonprofessional outpatient services.[193]

Not all tribal facilities are eligible to use the all-inclusive rate methodology for Medicare services.[194] In fact, it is only recently that tribal clinics have been authorized any recovery for Medicare Part B services.[195] Instead of using an all-inclusive rate, some tribal facilities must operate as Federally Qualified Health Centers, reimbursed under a cost reporting system subject to caps and co-payments. Though data are sparse, health care administrators sense that the all-inclusive rate would provide a higher reimbursement rate.[196]

Another major consideration is the requirement for co-payments. Native American patients are not required to pay for services received at IHS and tribal facilities. When the applicable insurance program requires a co-payment, the facility simply absorbs, or writes off, the cost.[197] The method of calculating the co-payment can potentially penalize the IHS facilities, in that the rate is set "at 20% of the national hospital charge for the procedure, which is nearly

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[188] Bob Newcombe, Alamo Navajo School Board, telephone interview, May 4, 2004.

[189] *Regarding the Reauthorization of the Indian Health Care Improvement Act H.R. 2440 and S. 556 Title IV and Amendments to the Social Security Acts: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Myra Munson, Sonosky, Chambers, Sachse, Miller & Munson, LLP). Furthermore, a 2002 agreement between CMS, IHS, and tribes exempted Indian health facilities from transitioning to a prospective payment system that would have eliminated this benefit. Shifting costs to accommodate a prospective payment system would have resulted in sizable cuts to health services for Native Americans. *See* Northwest Portland Area Indian Health Board, *2004 Legislative Plan*, Feb. 11, 2004, p. 8.

[190] IHS, Interrogatory Response 13.

[191] Ibid.

[192] Ibid.

[193] IHS, Interrogatory Response 16.

[194] Burgess interview; Newcombe interview.

[195] *Regarding the Reauthorization of the Indian Health Care Improvement Act H.R. 2440 and S. 556 Title IV and Amendments to the Social Security Acts: Hearing Before the Senate Comm. on Indian Affairs*, 108th Cong. (2003) (statement of Myra Munson, Sonosky, Chambers, Sachse, Miller & Munson, LLP).

[196] Burgess interview; Newcombe interview.

[197] MLI, "IA-00-165," p. 2.

always much higher than 20% of the payment rate, sometimes more than 50%."[198] The difference is additional cost that IHS facilities must write off using that reimbursement methodology, reducing the amount available for the purchase of additional health services.

Many of the remaining barriers to increased collection overlap with barriers to enrollment. For instance, as a simplified reimbursement mechanism, adopted temporarily to postpone the high expense of advanced billing systems, the all-inclusive rate has resulted in a combination of over- and underpayments.[199] In a similar light, just as the lack of training leads to a failure to enroll all eligible Native Americans in public health insurance programs, it also leads to billing errors and inefficiencies.[200] Staff who do not know, and are unable to determine, which services are billable will inevitably neglect to bill for all covered procedures.[201] As explained earlier, data on eligibility for enrollment in public insurance programs are incomplete. Without these data for comparison to collection figures it is difficult to estimate the extent of under-billing.

In addition, submitting improper or incomplete documents, failing to submit claims, and inadequately following up on pending claims lead to the denial of benefits and necessarily fewer collections.[202] Data problems, once again, make estimating the extent of this under-billing difficult at best.

Conclusion

The Commission finds that IHS funding levels are inadequate by every applicable standard of measurement and in every area of health service delivery within IHS. The lack of funding is, however, particularly acute for contract health services and urban Indian programs.

Federal policy, as expressed in numerous documents and declarations over the past century, reflects congressional intent to maintain credibility and to fully fund health care for Native Americans. Nevertheless, Myra Munson reminded us, "the ultimate policy document is always the budget document."[203] Unfortunately, the budget has clearly failed to reflect the stated policy objectives of providing adequate health care and erasing disparities. As a result, the federal government has defaulted on its obligation and responsibility to Native Americans. Considering the degree of inadequacy, the length of time over which it has been recognized, and

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[198] Ibid. Additionally, the study recommended that CMS set limits on co-payments for IHS and tribal facilities; increase the wage index to allow higher payments at IHS facilities; and provide an alternative reimbursement methodology similar to critical access facilities for the smaller IHS and tribal facilities—allowing higher reimbursement rates. Ibid.

[199] Dupree interview. Little to no data are available to evaluate this claim. Its basis is the pattern whereby Native Americans, who must travel long distances and sometimes bear difficult burdens to reach the care facility, tend to obtain many services on the same visit. For example, an individual might schedule a dental appointment and eye exam for the same visit originally planned for a diabetes follow-up. Regardless of the number of separate appointments provided on that visit, the all-inclusive rate pays for one outpatient visit. *See also* CMS, AAR Response, Addendum with recommended changes.

[200] Ibid.

[201] Ibid.

[202] Ibid. Dupree Testimony, Briefing Transcript, p. 213.

[203] Munson Testimony, Briefing Transcript, p. 214.

the obstinate refusal to take concrete action to remedy the situation, the only possible explanations are either discrimination or gross neglect on the part of the federal government.

The Commission has also determined that the current regulatory framework needlessly restricts IHS officials from making minor modifications to IHS facilities and structures, forcing inadequate facilities to remain in an unsatisfactory condition while waiting for increased appropriations specifically designated for that facility. In addition, current regulations requiring residence within defined Contract Health Service Delivery Areas allow the denial of access to health care for many Native Americans living off-reservation for the simple reason that they have exercised their right to live somewhere besides their home reservation.

Therefore, the Commission recommends the following:

- Congress should raise funding levels to reduce the national average FEHBP Disparity Index (FDI) from the current 52 percent to 80 percent. No federally funded program providing health care to Native Americans should be permitted to fall below an FDI of 60 percent. In the long term, Congress should raise funding levels to establish an average FDI of 100 percent.

- Congress, in all future IHS appropriations, should ensure that the IHS budget is adequate, independent of any consideration of increased third-party collections. In addition, Congress should include language in IHS appropriations specifically reaffirming that increases in third-party collections are not considered in determining IHS funding levels.

- Congress should establish a high-level investigative body to study changing Native American health care to an entitlement. This investigative body would also create a mechanism whereby the provision of health services to Native Americans by the federal government becomes mandatory and enforceable. This investigative body must include representatives from tribal and Indian advocacy organizations.

- Congress should immediately appropriate special funds for contract health services to a level sufficient to eliminate the rationing of health services for Priority I patients. The IHS, in consultation with tribal representatives, should establish this funding level; all future IHS appropriations must be justified with reference to this new, higher figure.

- Congress should immediately appropriate special funds for urban Indian programs to enable the establishment of programs capable of providing care at the level of reservation Indians. In more specific terms, the Commission recommends increasing appropriations by an amount equal to the per capita expenditures for current IHS users (as modified by the above recommendations) multiplied by the number of anticipated urban Indian program users. Future appropriations should be justified with reference to this new, higher figure.

- Congress should establish a mechanism to ensure that contract support costs are fully funded on an annual basis.

- Congress should enact legislation, similar to that in the proposed Indian Health Care Improvement Act, linking the 100 percent FMAP reimbursement to the individual patient rather than the facility used.

- Congress should establish a mechanism to ensure that future appropriations track with inflation.

- Congress should consider indexing increases in IHS appropriations so that, at a minimum, IHS program increases keep pace with increases in Medicaid and Medicare programs.

- The IHS should investigate mechanisms to allow increased decision-making authority at the tribal, area, and service unit level, particularly with respect to minor facilities modifications.

- The IHS should update the unmet need methodology to reflect more recent data on enrollment in private and public insurance programs, particularly in light of the identified discrepancies with the 25 percent third-party recovery figure.

- The IHS should develop an improved public education and outreach program to establish eligibility and facilitate enrollment in public health insurance programs, in order to maximize collection from alternate sources. Any efforts should incorporate the best practices from tribal programs with significant increases in third-party collections, including one-to-one interaction and oral communication modes.

- The IHS should improve its existing internal staff training efforts on the administration of public health insurance programs. Participation in such programs should be mandatory and ongoing for all staff responsible for managing, supervising, or advising Native Americans on eligibility and enrollment in public health insurance programs, and those involved in IHS third-party collection efforts.

- The IHS should establish measurable goals and timelines for increasing enrollment in public health insurance programs.

- The IHS should evaluate the current data management system and evaluate options for implementing a modernized health data system.

- The IHS should study the impact of creating a mechanism that would enable appropriated funds to be spent on urban Indians, outside Title V programs.

- The IHS should evaluate its method for using historic cost data in its negotiation of all-inclusive rates, with an eye towards using more current cost report data. Alternatively, IHS should develop a mechanism, whereby adjustments can be made to reflect actual cost rates at time of service.

- The IHS should evaluate the current IHCIF program, with an eye toward developing an alternative that can provide a more realistic approach to resolving inequities between the various tribal programs.

- The IHS should monitor the third-party recovery efforts of individual IHS facilities and take corrective action to raise collections in delinquent programs.

- The CMS and IHS should evaluate the current Medicare/Medicaid reimbursement mechanisms available to Native Americans, with an eye toward establishing a program, combining elements of the Qualified Indian Health Program and critical access facility programs proposed in IHCIA and interagency agreements, that will enable full and adequate recovery while operating within the confines of the present and anticipated IHS data systems.

- The CMS should encourage state Medicaid programs to participate in the Medicaid Administrative Matching program, particularly with regard to Native American programs.

- The CMS should encourage state Medicaid programs to provide state representatives in IHS and tribal facilities, utilizing the Medicaid Administrative Matching program where applicable. If necessary, CMS should incorporate additional incentives.

- The CMS should consider modifying its six-month re-determination requirement for Medicaid and SCHIP eligibility.

- The CMS should re-evaluate its decision with respect to Native American waivers in state-operated CMS programs, in light of the unique political status of Native Americans. The CMS should encourage state Medicaid programs to establish waivers similar in effect to the 100 percent FMAP program.

- The CMS should evaluate the feasibility of providing equitable relief for those elderly Native Americans who fail, as a result of federal programs and policies, to qualify for Medicare under the 40-quarter requirement. Specifically, equitable relief should establish enrollment eligibility for those Native Americans who otherwise fail to qualify for Medicare as a result of government policies. This equitable relief could be similar in form to that provided to those Native Americans who failed to enroll in Medicare as a result of faulty enrollment guidance. In those circumstances, relief has been provided by granting waivers from the surcharge for late enrollment in Medicare Part B.

- The CMS should conduct an evaluation of the sufficiency of federal regulations governing administration of Medicaid and Medicare programs by IHS and tribal facilities, to ensure that administrative guidance is consistent and fully developed.

Chapter 5: Proposed Legislative Changes Affecting Native American Health Care

Officials of the Indian Health Service (IHS) have explored new and innovative ways to extend resources and address the causes of existing disparities in the health status and outcomes for Native Americans. This is a collaborative effort. At times, change originates within the agency; at other times, it comes through tribal consultation or other means. Inevitably, all branches of the federal government influence both long-term and day-to-day IHS operations. Seemingly minor changes trickle down with enormous impact. This chapter addresses proposed legislative changes to the current system, including points of contention.

Legislative Changes

This section on legislative change identifies and addresses federal legislation with the potential to significantly affect the delivery of health services to Native Americans and the current disparities in health status and outcomes. Significant legislative initiatives include the reauthorization of the Indian Health Care Improvement Act (IHCIA), the Closing the Health Care Gap Act of 2004, the Health Care Equality and Accountability Act, and the Tribal Contract Support Costs Technical Amendments of 2004.[1]

Reauthorization of the Indian Health Care Improvement Act

Among the pending changes identified thus far, the reauthorization of the Indian Health Care Improvement Act appears to hold the most promise for improving the lives of Native Americans. The proposal for reauthorization of IHCIA is a tribally prepared, far-reaching proposal for addressing every aspect of providing medical care to Native Americans. Tribal leaders initiated the proposed legislation; the final version is the product of years of consultation between tribal leaders and federal government representatives.

Anticipating the expiration of IHCIA, IHS organized regional consultation meetings with tribal leaders in 1998 to solicit input on changes to the Act.[2] Based on the outcome of the regional consultation meetings, the tribes formed a National Steering Committee (NSC) of tribal leaders to draft a comprehensive proposal that would address a range of health care concerns

[1] In the early stages of this report, a variety of Medicare proposals were discussed for inclusion in this section. Subsequently, President Bush signed into law the Medicare Prescription Drug, Improvement, and Modernization Act of 2003. According to IHS Director Dr. Charles Grim, several items will be particularly important to Native Americans, including a provision to increase rural ambulance reimbursement rates, a provision to compensate IHS for providing emergency assistance to undocumented aliens, a provision to require Medicare hospitals to accept Medicare rates as payment in full from IHS users, an expansion of Medicare part B services in IHS facilities, and changes to Critical Access Hospital reimbursement rates. *See* U.S. Department of Health and Human Services, Indian Health Service, "IHS Director Grim Congratulates Bipartisan Passage of Medicare Bill; 'Bill Benefits All Americans and Has Specific Benefits for Indian Country,' Director Says," press release, Dec. 9, 2003, p. 1.

[2] U.S. Department of Health and Human Services, Indian Health Service, "Overview of Consultation Process," <http://www.ihs.gov/AdminMngrResources/reauthor/ Our_Initiative.cfm> (last accessed Dec. 19, 2003).

using the reauthorization of IHCIA.[3] The NSC specifically sought to make IHCIA more responsive to current real-world needs, to increase opportunities for attracting more revenue into the health system, and to facilitate greater exercise of self-determination in health care program decision-making and regulations.[4]

There is no single change in the reauthorization of IHCIA that will close the health status gap for Native Americans. Instead, the House and Senate bills, as proposed, attempt to address many of the contributing problems by including provisions aimed at increasing access to appropriate health facilities, increasing access to and enrollment in health insurance programs, increasing federal funding, improving the quality of care, decreasing poverty, and increasing the level of educational attainment for Native Americans.

The reauthorization of IHCIA attempts to accomplish these tasks through a series of procedural changes to the established system and the adoption of seven health care objectives identified by the National Indian Health Board:

1. Health Objectives. Adopts the policy, for the first time, that health improvement objectives must be the same for American Indians and Alaska Natives as for all other Americans.
2. Self-Determination & Self-Governance. Updates the Act to recognize that, since 1992, tribes and tribal organizations are operating more than half of IHS programs.
3. Continuum of Care. Provides authorization for a full range of health programs, rather than relying on "demonstration projects," so that IHS, tribes, and urban Indian organizations can take advantage of opportunities and set priorities that specifically respond to the needs of the local population.
4. Home and Community-Based Care. Updates the Act to focus on "programs" instead of "facilities" in recognition that, nationally, the length of stay in hospitals has decreased in favor of other care models.
5. Facility Funding Flexibility. Authorizes more flexible funding alternatives and inter-agency funding partnerships to help reduce the backlog in facility construction and maintenance.
6. Behavioral Health. Authorizes integration of mental health, substance abuse, and violence programs into a behavioral health program to provide more efficient and higher quality care.
7. Access to Medicare and Medicaid. Expands access to recovery from Medicare and Medicaid through amendments to IHCIA and the Social Security Act and provides for a study of reimbursement.[5]

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[3] Ibid. Tribal representatives include one tribal member from each of the IHS established areas, one self-governance representative, and one urban representative. *See* National Indian Health Board, "NSC Member List," <http://www.nihb.org/docs/nsc_member_list.doc> (last accessed Apr. 7, 2004).

[4] Carol Barbero, partner, Hobbs, Straus, Dean & Walker, interview in Washington, DC, Aug. 11, 2003; Myra Munson, Sonosky, Chambers, Sachse, Miller & Munson, LLP, interview in Washington, DC, Aug. 11, 2003.

[5] National Indian Health Board, "Reasons To Support the Indian Health Care Improvement Act H.R. 2400 and S. 556," <http://www.nihb.org/docs/ihcia_reasons_to_support.pdf> (last accessed Dec. 19, 2003).

To accomplish these objectives, the reauthorization of IHCIA is organized into eight titles. The first three cover manpower, services, and facilities, respectively. The fourth title, access to health services, addresses access by way of public insurance programs. Urban Indian programs are administered separately under Title V. Structural changes are implemented through the title on organizational improvements. The relatively new change in focus to behavioral health is formalized in Title VII, followed by the catchall title for miscellaneous items.

Each of these titles will be explained in detail below, including how individual provisions in each title will improve the health status of, or the service provided to, Native Americans. The IHCIA is an extensive piece of legislation, addressing the affordability, availability, accessibility, and acceptability of health care. Only the major provisions, having a significant impact on improving the health status of Native Americans, are explained.

Title I: Indian Health Manpower. The changes in Title I primarily address the scholarship programs for health professionals. By broadening the health disciplines open to scholarships, decentralizing the decision-making process, and encouraging scholarship recipients to serve the area from which they receive their scholarship, the tribes will begin to address the problems with recruiting and retention in isolated areas, while obtaining the services of more culturally proficient health care providers.[6] In addition, provisions also eliminate current demonstration projects, contingent upon the establishment of permanent funding sources for scholarship programs.[7]

Title II: Health Services. The changes in Title II, in broad terms, aim to improve the quality of health service programs providing care to Native Americans. Improvement will be accomplished by institutionalizing the national diabetes program that is currently funded by special appropriations;[8] decentralizing control of the Catastrophic Health Emergency Fund to the area level; expanding preventive services to cover all cancers, instead of limiting coverage to mammography screening for breast cancer; establishing epidemiology centers in all 12 areas; requiring staff in tribally operated facilities to meet the same licensing requirements as IHS facilities; strengthening the prohibition against contract health service providers holding individual patients responsible for payment for contract health services obligations;[9] establishing a program to monitor nuclear and environmental health hazards; and designating the entire state of Arizona as a Contract Health Service Delivery Area.[10]

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[6] *Indian Health Care Improvement Act Reauthorization Amendments of 2004: Hearing on H.R. 2440 before the House Resources Committee*, 108th Cong. (2003) (testimony of Joe Shirley, president, Navajo Nation) (hereafter cited as Shirley House Testimony); *Reauthorization of the Indian Health Care Improvement Act: Hearing on S. 212 and H.R. 2440 before the Senate Committee on Indian Affairs and the House Resources Committee*, 107th Cong. (2003) (testimony of Rachel A. Joseph, co-chair National Steering Committee) (hereafter cited as Joseph Joint Testimony).

[7] Joseph Joint Testimony.

[8] *Indian Health Care Improvement Act Reauthorization of 2000: Hearing on S. 2526 before the Senate Committee on Indian Affairs*, 106th Cong. (2000) (testimony of John J. Callahan, Assistant Secretary for Management and Budget, HHS) (hereafter cited as Callahan Senate Testimony).

[9] Joseph Joint Testimony.

[10] Shirley House Testimony.

Title III: Health Facilities. As a starting point, Title III will institutionalize tribal consultation for facilities expenditures. This change will ensure that facilities decisions accurately reflect the needs and priorities of the affected populations.[11] In addition, the consultation will result in a priority system that encompasses all facilities, not just a "top 10." This change ensures that a true and complete spectrum of unmet need in Indian Country is presented.[12] Concerning accreditation, Title III will authorize accreditation under any nationally recognized accrediting authority. Doing so will expand the ability of smaller facilities to meet eligibility requirements for public insurance programs, increasing the funding available to purchase additional health care for Native Americans.[13] Several of the other changes involve the creation of more flexible funding options. These include the creation of IHS-tribal joint ventures; allowing for innovative financing by tribes, coupled with an IHS commitment to equipment and staffing; the creation of a Health Care Facilities Loan Fund; and express permission to use any "other source" of funds for tribal services to provide health care. A provision is included to ensure that the use of other sources by tribes will not jeopardize their positions on the priority list for future construction projects.[14] These flexible funding options have the potential to significantly increase the operating funds available to tribally operated facilities and will serve as a multiplier for federal funding.

Title IV: Access to Health Services. Title IV attempts to eliminate the barriers that prevent Native Americans from accessing public health insurance programs. By eliminating these barriers, reimbursement from third parties is increased and additional funding made available to purchase health care for Native Americans who otherwise might not receive care. Specific provisions eliminate barriers by amending the Social Security Act to authorize reimbursement to IHS facilities for all services for which Medicare/Medicaid programs pay, creating Qualified Indian Health Programs, creating a waiver of Medicare's late enrollment fee for Native Americans, extending 100 percent FMAP to all health services provided to Native Americans,[15] allowing tribal facilities to deal directly with the Department of Health and Human Services (HHS) on Child Health Insurance Program issues, allowing for the waiver of all cost sharing by IHS eligible patients enrolled in public insurance programs, preventing the mandatory enrollment of Native Americans in managed care programs as a precondition to enrollment in public insurance programs, and establishing a demonstration project for the direct billing of Medicare/Medicaid by tribally operated facilities.[16]

Title V: Health Services for Urban Indians. As the label suggests, Title V contains most of the provisions regarding urban Indians. It attempts to raise the health status of urban Indians by requiring HHS agencies to consult with urban Indians before taking action that would affect

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[11] Ibid.

[12] Joseph Joint Testimony.

[13] Ibid. Callahan Senate Testimony.

[14] Joseph Joint Testimony.

[15] Qualified Indian Health Programs, 100 percent FMAP, and Medicare's late enrollment waiver are discussed in detail later in this chapter.

[16] Joseph Joint Testimony. This section includes the establishment of Navajo Nation Medicaid Agency. Currently, with the Navajo Nation crossing three state borders, tribally operated facilities have three sets of rules. This change will allow the Navajo Nation to deal directly with Medicaid under its own set of rules. *See* Shirley House Testimony.

them; expanding HHS authority to fund urban Indian programs through grants, loans, and loan guarantees; and enabling urban Indians to enjoy the protection of malpractice coverage under the Federal Tort Claims Act.[17] In addition, this title makes permanent the Oklahoma Demonstration Projects in Tulsa and Oklahoma City. These demonstration projects are urban Indian clinics that have been funded through the more reliable Hospitals and Clinics account.[18]

Title VI: Organizational Improvements. The major provision of Title VI is the elevation of the director of IHS to an assistant secretary in HHS. This elevation would "provide a stronger coordination and advocacy role in budget and policy matters related to Indian health" for the director, with a corresponding effect on the stature of the IHS program.[19] Presumably, this would result in changes in HHS policy and procedure that benefit IHS and raise the health status of Native Americans.

***Title VII: Behavioral Health Programs*.** Title VII's primary focus is to establish a "continuum of care." Specifically, it establishes a "seamless and comprehensive treatment model for behavioral health that is inclusive of substance abuse and mental health disorders."[20] Combining the various behavioral health issues in one system will allow for more effective assessment and treatment in a holistic manner in one facility, limiting referral of individual patients to several agencies or facilities to address unified conditions.[21] In addition, this title provides for the establishment of at least one in-patient mental health facility for each IHS area, a significant expansion of current mental health treatment capacity.[22]

Title VIII: Miscellaneous. This final title contains an assortment of minor provisions. Its most significant provision provides for the establishment of a National Bipartisan Indian Health Care Entitlement Commission. This provision implicitly recognizes that several issues preclude transforming health care for Native Americans into an entitlement during this reauthorization.[23] The purpose of the bipartisan commission is to resolve those issues and make lasting improvements to the manner in which health care for Native Americans is funded.

As mentioned above, the proposed reauthorization of IHCIA recognizes that many, and in some areas most, tribes have assumed responsibility for administering their own health programs under contracts and compacts.[24] While tribes rely on government funding, the reliance is to

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[17] Joseph Joint Testimony.

[18] *Indian Health Care Improvement Act: Hearing before the Senate Committee on Indian Affairs and the House Resources Committee*, 107th Cong. (2003) (testimony of Everett R. Rhoades, vice president, Central Oklahoma American Indian Health Council). There are currently two major issues unresolved with this section of IHCIA. The first issue is whether these projects are subject to tribal control. The second issue is whether these facilities are operating units or service units, which determines whether they are subject to allocations from the service unit or from the IHS. *See* ibid., pp. 4, 8.

[19] Callahan Senate Testimony.

[20] Shirley House Testimony.

[21] Ibid.

[22] Joseph Joint Testimony.

[23] Ibid.

[24] Today, tribes administer more than half of IHS funding through self-determination contracts or self-governance compacts. There are 61 self-governance tribal compacts and 81 funding agreements representing 285 tribes. *See Tribal Self-Governance Amendments of 1998: Hearing on H.R. 1833 before the Senate Indian Affairs Committee*,

varying degrees. Many tribes have found it necessary to access tribal money, charitable grants, and other funding sources. The new bill will allow for additional and more flexible funding options, as explained above.[25] In addition to these options, the reauthorization will produce gains in direct funding for health care. Specifically, the improvements identified above would generate at least an additional $6.9 billion for direct spending on Native American health care over the next 10 years.[26]

Reauthorization of IHCIA will not be automatic. Its recent history predicts some resistance. The most recent version of the Indian Health Care Improvement Act was passed in 1992 and authorized through FY 2000; Congress extended it through FY 2001.[27] In October 1999, the NSC delivered its first proposal for modifications to IHCIA to the President and Congress.[28] The IHCIA reauthorization bills introduced in both the 106th and 107th sessions of Congress adopted most of the changes proposed by the steering committee.[29] While hearings were held on the Senate bill, neither of the Senate bills ever reached the floor. In September 2002, the administration voiced reservations on the costs associated with the mandatory spending provisions of the Senate bill.[30] To address the cost concerns expressed by the administration, the NSC and members of the House began negotiations to revise the draft bill.

Despite the fact that negotiations to modify the Senate bill were underway in the House, Senator Ben Nighthorse Campbell introduced Senate bill 556 in March 2003.[31] Subsequently, the Senate Indian Affairs Committee conducted hearings, even though Senate bill 556 was identical to the earlier bills objected to by the administration.

In June 2003, Representative Don Young introduced a bill containing the revisions negotiated by the NSC and members of the House to address the concerns of the Bush administration.[32] Unlike the Senate bill, the House bill does not include three particularly noteworthy provisions:

- The Qualified Indian Health Program (QIHP).

105th Cong. (1998) (testimony of Luana Reyes, director of headquarters operations, Indian Health Service, U.S. Department of Health and Human Services). *See also* the detailed discussion in Chapter 3.

[25] One example of a "flexible funding option" is allowing tribes to use private credit sources to finance construction of health facilities, yet allowing the Congressional Budget Office (CBO) to score the expense as an operating lease when the facility is leased from the tribes to IHS. *See* Joseph Joint Testimony.

[26] Congressional Budget Office, *Preliminary CBO Estimate of the Effects on Mandatory Spending of S. 212*, the Indian Health Care Improvement Act Reauthorization of 2001, Mar. 30, 2001. *See also* Munson interview.

[27] Efforts to reauthorize IHCIA before the bill's sunset date were hampered by, among other things, Congress' focus on other matters, primarily homeland security.

[28] The structure of IHCIA has been retained in the various reauthorization bills introduced to Congress with new and revised language inserted in all eight titles.

[29] S. 212, 107th Cong. (2001)—A bill to amend the Indian Health Care Improvement Act to revise and extend such Act; S. 2526, 106th Cong. (2000)—A bill to amend the Indian Health Care Improvement Act to revise and extend such Act.

[30] In March 2001, the CBO estimated the federal budget impact of the mandatory spending parts of the Senate bill, S. 212. The CBO estimated these would cost $6.9 billion over 10 years. Munson interview.

[31] S. 556, 108th Cong. (2003)—Indian Health Care Improvement Act Reauthorization of 2003.

[32] Indian Health Care Improvement Act Amendments of 2003, H.R. 2440, 108th Cong. (2003).

- The exemptions from late enrollment penalty under Medicare Part B for Native Americans.
- The proposed 100 percent Federal Medical Assistance Percentage (FMAP) for Medicaid eligible Native Americans treated at facilities other than tribal or IHS facilities.

The QIHP would have established a new category of provider, eligible for full-cost reimbursement under Medicare, Medicaid, and the Children's Health Insurance Program. Under current cost recovery procedures, many programs providing services to Native Americans utilize the all-inclusive rate.[33] The QIHP would have enabled facilities to select from several payment options, including the full-cost recovery method, which would also allow recovery for indirect costs.[34] The QIHP would have also expanded the list of covered services to include "preventive primary care; SCHIP services; various immunizations; patient transportation; and services performed by an employee licensed/certified to perform such services that would be reimbursable if performed by a physician."[35] Finally, the provision would have allowed IHS, tribes, and urban Indian programs to qualify for QIHP designation.[36] The Congressional Budget Office estimates a 10-year benefit of $2.2 billion if the QIHP provision is implemented.[37] That $2.2 billion would represent additional funding available for use by tribal programs in providing health care to Native Americans.

The provision excluding Native Americans from paying a late enrollment penalty for Medicare Part B was designed to prevent the elderly from delaying enrollment in Medicare until they become ill.[38] As discussed in Chapter 4, the absence of relevant data, as well as the ineligibility due to lack of qualifying quarters, makes it difficult to estimate how widespread the problem is with under-enrollment in Medicare. Nevertheless, to the extent that Native Americans are under-enrolled in Medicare, a significant source of funding is neglected, with a consequent reduction in the availability of health services that funding would provide for uninsured Native

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[33] Joseph Joint Testimony. *See also* the discussion in Chapter 4 on the "all-inclusive rate."

[34] Joseph Joint Testimony.

[35] Ibid.

[36] In addition to financial concerns, the provision was dropped because HHS claimed that the provision was extremely complex and not feasible to administer. Specifically, the QIHP would:

> require the Federal government to complete a series of complex payment computations for each ITU provider, for each payment period, (including rates and adjustments not available to any other provider) to identify the provider type for each that yields the highest payment amount for that period. However, such computations could only be made after services are provided, when it is too late for providers to have known or complied with the differing conditions of participation applicable to differing provider types.

See U.S. Department of Health and Human Services, Indian Health Service, Response to the Commission's Interrogatory 26, April 2004 (hereafter cited as IHS, Interrogatory Response). *See also* U.S. Department of Health and Human Services, Centers for Medicare and Medicaid Services, Response to the Commission's Interrogatory 7, June 2004 (hereafter cited as CMS, Interrogatory Response).

[37] Congressional Budget Office, *Preliminary CBO Estimate of the Effects on Mandatory Spending of S. 212, the Indian Health Care Improvement Act Reauthorization of 2001*, Mar. 30, 2001. *See also* Munson interview.

[38] IHS, Interrogatory Response 27. *See also* Barbero interview; Munson interview (The HHS objected to this provision because it would treat Native Americans differently from other Medicare-eligible persons who are penalized because they do not timely enroll). The HHS refers to the desired change as enabling adverse selection, where patients delay until they are ill with costly health conditions before enrolling. Because of the obvious negative financial consequences, HHS objects. *See* CMS, Interrogatory Response 8.

Americans. Although few tribal leaders interviewed had solid numbers on the benefits of this provision, one principle was clear: as the ability of the tribes to persuade their elderly members to join increases through compacting, the ability to grant a waiver to those exposed to Medicare for the first time will significantly enhance third-party recovery.[39]

Finally, the House bill deleted the provision that assigned the 100 percent Federal Medical Assistance Percentage (FMAP) to services provided to Medicaid-eligible Native Americans referred by IHS or tribal programs to outside providers through the Contract Health Services program. Under current law, 100 percent FMAP reimbursement for treatment applies only to services provided to Native Americans directly by an IHS or tribal facility.[40] When Native Americans are treated in non-IHS facilities, states are reimbursed only at the standard rate. Consequently, states are required to pay as much as 50 percent of the cost of providing health care to Native Americans in non-IHS facilities. Without that full reimbursement accompanying 100 percent FMAP status, states have no incentive to enroll Native Americans in Medicaid, fewer Native Americans are enrolled, and less money is available to purchase additional health services. In addition, if receiving 100 percent reimbursement, an individual state providing service experiences less economic pressure as well as less pressure to reduce benefits for all patients.

These three provisions were ultimately dropped because of costs and IHS concerns about the difficulty of implementation. Most importantly, the Congressional Budget Office estimated these programs would be too costly. Over the 10-year period from 2002 to 2011, it was estimated that the QIHP provision would cost $2.2 billion, the Medicare exemption would cost $545 million, and the FMAP provision would cost $2.3 billion.[41] In addition, IHS complained that the changes to the QIHP provider type would introduce significant complications to the operation and structure of the payment systems, and that 100 percent FMAP would substantially increase program and administrative costs while not guaranteeing an increase in actual services.[42] The Commission finds the latter explanation unconvincing. Certainly, administrative expenses would not consume the entire $2.3 billion. The IHS recognized this implicitly in explaining that the adoption of the 100 percent FMAP provision would "shift all, rather than part of the costs for existing services from the state to the federal budget."[43] This shift represents an influx of funds available to provide additional health services for Native Americans that otherwise would not have been provided.

With or without the three redacted provisions, IHCIA would be a dramatic step forward in the effort to erase current disparities. If passed, IHCIA would enable significant improvement

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[39] Alan Burgess, tribal health administrator, Owyhee Community Health Facility, telephone interview, May 12, 2004. The HHS maintains that as enrollment increases this problem will eventually fade. *See* CMS, Interrogatory Response 8.

[40] Barbero interview; Munson interview (in addition to the cost factor, this provision was dropped because the states, not Native American health programs, gained the financial advantage).

[41] Congressional Budget Office, *Preliminary CBO Estimate of the Effects on Mandatory Spending of S. 212, the Indian Health Care Improvement Act Reauthorization of 2001*, Mar. 30, 2001. *See also* Munson interview.

[42] *See Reauthorization of the Indian Health Care Improvement Act: Hearing on S. 556 before the Senate Comm. on Indian Affairs*, 107th Cong. (2003) (testimony of Dr. Charles W. Grim, director, IHS). *See also* CMS, Interrogatory Response 9.

[43] *See* IHS, Interrogatory Response 11.

in the health care provided to Native Americans. If passed in the Senate version, as originally proposed by the NSC, it would accomplish far more. For pragmatic reasons, IHCIA National Steering Committee has reached a consensus that members should support passage of H.R. 2440 in its current form.[44] Losing the three provisions identified above would be a small price to pay for the many significant gains provided by passage of the remaining provisions.

Passage in either form is not guaranteed, nor is the timing. If passage is to occur this year, "the expectation is that [it] will be passed this summer, before the fall presidential and congressional election activities get in full swing."[45] Meanwhile, the tribes must continue to wait. Fortunately, IHCIA is not the only legislative effort with the potential to improve health care for Native Americans; other proposed legislation is discussed next.

Other Proposed Legislation Relevant to Native Americans

The regular reporting of Native American health disparities is one method of highlighting the health problems plaguing Native Americans and encouraging a more rapid response from lawmakers responsible for ensuring Native Americans are provided the health care they were promised. A series of reports and publications by various governmental and nongovernmental organizations have engaged in that effort. Most recently, the publication of *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* by the Institute of Medicine documented the overwhelming health disparities between people of color and whites and spurred Congress to engage the issue of health disparities.[46] As a first step, Congress commissioned the Government Accounting Office (GAO) to identify approaches for eliminating the identified disparities and report their findings.[47] In the aftermath of the GAO report, Congress introduced two similar acts of legislation, the Closing the Health Care Gap Act of 2004 and the Health Care Equality and Accountability Act, introduced by Senators Bill Frist and Tom Daschle, respectively. [48] The primary difference between the two is that the Health Care Equality and Accountability Act focuses on ethnic minority populations, whereas the Closing the Health Care Gap Act of 2004 expands disparities to include all populations subject to disparity.[49] In addition, the Health Care Equality and Accountability Act seeks to expand health insurance coverage, in

[44] Northwest Portland Area Indian Health Board, *2004 Legislative Plan*, Feb. 11, 2004, p. 4. *See also* IHS, Interrogatory Response 26, 27, and 28.

[45] Dr. Charles W. Grim, "An Indian Health Update" (speech before the Midwest Alliance of Sovereign Tribes Impact Week Meeting, Mar. 22, 2004).

[46] Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (National Academies Press, Washington, DC, 2002), p. 19 (hereafter cited as IOM, *Unequal Treatment*).

[47] United States Government Accounting Office, *Health Care: Approaches to Address Racial and Ethnic Disparities*, GAO-03-862R, cover letter, July 8, 2003, <http://www.gao.gov/new.items/d03862r.pdf> (last accessed Feb. 9, 2004). Although specific disparities in the health status of Native Americans are identified in the report, the recommendations apply to minorities across the board.

[48] Closing the Health Care Gap Act of 2004, S. 2091, 108th Cong. (2004); Health Care Equality and Accountability Act of 2003, S. 1833 and H.R. 3459, 108th Cong. (2004).

[49] Marsha Lillie-Blanton, Kaiser Family Foundation, "Ask the Experts: Racial and Ethnic Disparities" (transcript of teleconference of Apr. 5, 2004) p. 30.

contrast to the Closing the Health Care Gap Act of 2004, which seeks to expand awareness of programs already in place.[50]

Closing the Health Care Gap Act of 2004

The Closing the Health Care Gap Act of 2004[51] was introduced as "the next bold and necessary step to reduce and eliminate health disparities."[52] This legislation would address five key elements:

- Expanded access to quality health care.
- Strong national leadership, cooperation, and coordination.
- Professional education, awareness, and training.
- Enhanced research.
- Clinical disease prevention and management services.[53]

As part of the access element, the bill would establish a health care access grant program and broaden and expand outreach programs. These outreach programs would increase enrollment in public insurance programs and target and reduce behavioral risk factors.[54] Perhaps most importantly, the new programs would create programs to drastically reduce the number of uninsured. To the extent this increases the enrollment of Native Americans in public health insurance programs, it would increase the number of health services provided to Native Americans by increasing third-party collections and making more money available to the individual health programs. This element's inclusion of prevention programs parallels recent IHS efforts and elements of IHCIA in elevating the role prevention plays in raising the health status of Native Americans.

The second element, national leadership, focuses on the HHS Office of Minority Health and would expand its mission and authority.[55] Specifically, the Office of Minority Health would establish new goals for addressing health care disparities, coordinate data collection and assessment of disparities, and work with other agencies to "maximize program resources available to reduce and eliminate disparities."[56] Whether this element will improve the health status of Native Americans, and whether it will improve the quality or quantity of health services provided, will depend on its implementation. Presumably, Native Americans will, in many respects, gain when resources are combined. More specifically, when money previously spent on administration is subsequently available for health services—including health services for Native Americans—Native Americans will gain. However, if the elimination of administrative resources

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[50] Ibid.

[51] Closing the Health Care Gap Act of 2004, S. 2091, 108th Cong. (2004).

[52] "Legislative Summary for the Closing the Health Care Gap Act of 2003," <http://www.allhealth.org/recent/audio_10-10-03/FristBillSummary.doc> (last accessed Mar. 2, 2004).

[53] Ibid.

[54] Ibid.

[55] Ibid.

[56] Ibid.

results in the deterioration of important system characteristics uniquely beneficial to Native Americans, then consolidation could reduce the quality of care provided to Native Americans.

Professional education, the third element, would expand existing programs to increase the number of minorities in the health professions. It would also establish a demonstration project to test model criteria for cultural competence, while also identifying barriers to culturally appropriate care.[57] To the extent that this element is able to increase the number of Native American health care providers, it will be successful in raising the standard of care by improving cultural competence and reducing problems associated with recruiting and retention.

The enhanced research element would sponsor additional research to assess intervention strategies and to examine the ethical issues associated with health care disparities.[58] This element will prove successful to the extent that the body of knowledge gained through its efforts is implemented into the programs directly serving Native Americans.

The final element of this legislation would establish special programs, perhaps modeled after the successful Native American diabetes programs, to improve services in targeted areas disproportionately affecting minority populations, including "cancer, asthma, obesity, cardiovascular disease, HIV/AIDS and infant mortality."[59] As the Native American population is disproportionately affected by these indicators of health status, the implementation of this element will raise the health status of Native Americans, so long as tribal and IHS facilities are included among those programs benefited by this element.

For all of the identified elements above, one risk to Native American programs is that new programs will be created without the accompanying appropriated funding. To the extent that funding for these programs must come from the current IHS budget, in effect reducing funding for Native Americans by dividing funding among a larger group, this legislation would represent a threat to the health status of Native Americans. In that sense, this bill would "soft-pedal the racial dimension of unequal medical treatment and create a dangerous precedent for health policy."[60] It is essential that Congress provide the funding to support all requirements mandated by this legislation.

The tribes have had little time to analyze the provisions of the Closing the Health Care Gap Act of 2004 , and less to consult and prepare a formal response.[61] Accordingly, no tribal opinions were obtained with regard to either of the two bills. Nevertheless, it is certain that any loss of funding would be a primary concern with passage of any health care legislation. In addition, tribal consultation has become an expected part of the process with regard to legislation affecting Native Americans. Any attempt to divorce tribal leaders from the legislative process would likely encounter similar resistance. To the extent that the provisions of the Closing the Health Care Gap Act of 2004 parallel those from the Indian Health Care Improvement Act, these consultation concerns could be alleviated. As previously explained, elements of the Closing the Health Care Gap Act of 2004 are written to address disparities for all "disparity populations," not

[57] Ibid.

[58] Ibid.

[59] Ibid.

[60] American Health Line, *Health Disparities: Frist Bill Would Emphasize Poverty Factor*, Mar. 30, 2004.

[61] Chris Walker, executive director, Cherokee Health Services, interview in Washington, DC, Apr. 23, 2004.

merely an identified minority group. By illustrating the comparable problems faced by the various minority groups, the provisions of the Closing the Health Care Gap Act do indeed parallel at least some of the provisions of the Indian Health Care Improvement Act. In a similar manner, the next bill, the Health Care Equality and Accountability Act, also draws parallels with the Indian Health Care Improvement Act.

Health Care Equality and Accountability Act

The Health Care Equality and Accountability Act is another broadly worded bill designed to reduce disparity for all people of color.[62] Of particular note is a provision specifically addressing funding for Native American health care, in addition to many provisions paralleling those in the Closing the Health Care Gap Act.

Title I, subtitle D, of the Act addresses Indian health care funding and provides for an immediate and dramatic increase in funding.[63] It also details the mechanism for calculating future increases in light of population growth and inflation. One very controversial aspect makes the funding an entitlement, by removing it from the appropriations process.[64] Other provisions specifically targeting improved health care for Native Americans include:

- Provision of health promotion and disease prevention services.
- Monitoring by the Federal government of environmental and nuclear health hazards and provision of appropriate medical care.
- Implementation of a 10-year funding plan to provide a safe water supply, sanitary sewage, and solid waste disposal facilities.
- Development of a comprehensive behavioral health prevention and treatment program.[65]

In addition, the act would include requirements for enhanced racial, ethnic, and primary language data collection, analysis, and reporting from every health-related program receiving federal funds from the Department of Health and Human Services—to increase accountability and to strengthen the safety net of public insurance programs.[66] In addition to a national data program, the legislation authorizes the establishment of more epidemiology centers, designated specifically to serve the Indian health programs.[67]

Passage of this legislation would accomplish many of the same objectives identified for IHCIA, and more. Namely, it would raise the funding levels to the point where adequate care could feasibly be provided; it would provide for the data collection necessary to truly understand the problems affecting Native Americans and develop appropriate programs in response; and

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[62] Health Care Equality and Accountability Act of 2003, S. 1833 and H.R. 3459, 108th Cong. (2004).

[63] *Id.* § 141.

[64] *Id.*

[65] Office of Rep. Donna Christensen, "Detailed Summary of the Health Care Equality and Accountability Act of 2003" (provided by fax, Oct. 23, 2003).

[66] Ibid.

[67] Ibid.

finally, it would bolster the two program types requiring additional attention in the evolving health care programs serving Native Americans—behavioral health and preventive services.

Tribal Contract Support Costs Technical Amendments of 2004

In the discussion of contract support costs (CSC) in Chapter 4, one concept clearly emerged: CSC funding enables tribal programs operating under the Indian Self-Determination and Education Assistance Act to develop the necessary infrastructure for operating successful health care programs.[68] Unfortunately, one overriding truth associated with contract support costs is that, for many tribes, those costs have never been fully funded. Chapter 4 described the litigation initiated to recover unpaid contract support costs. It is important to note here that, subsequent to the years covered by this litigation (1996–1997), Congress has included "capped" line item appropriations for contract support costs, effectively limiting annual contract support costs to the limited amounts requested by IHS in the annual budget process.[69] It is that use of "caps" that makes new legislation necessary even if the Supreme Court rules in favor of the tribes.[70] The next section addresses legislation introduced to remedy the contract support costs underfunding in the future.

On March 8 of this year, Senator Campbell introduced Senate bill 2172, the Tribal Contract Support Costs Technical Amendments of 2004.[71] This legislation would change the current contract support costs funding authorization by removing the provision that makes funding subject to the availability of appropriations and inserting a clause that authorizes appropriations to cover any unpaid costs.[72]

This legislation is a first step in addressing tribal concerns, but falls short in its "lack of clarity."[73] To the extent that the funds to be appropriated under the Act may come from either the lump sum IHS appropriation or from supplemental appropriations, it becomes an entitlement. Contract support costs will be paid. If the funds are distributed from the lump sum appropriation, presumably health services must be reduced elsewhere to cover the additional mandate. In doing so, the payment of contract support costs acts merely as a redistribution of resources, in favor of tribes participating in the tribal self-governance processes.[74] Consequently, S.2172, as introduced, should be amended to provide the necessary clarification.

Failing to fully fund contract support costs represents a penalty to tribes choosing to participate in the tribal self-governance programs. Enacting appropriate legislation would be a significant step toward improving the health status of Native Americans by making more funding

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[68] *See* Chapter 4. *See also Tribal Contract Support Cost Amendments of 2004: Hearing on S. 2172 before the Senate Comm. on Indian Affairs*, 108th Cong. (2004) (testimony of Charles W. Grim, director, Indian Health Service) (hereafter cited as Grim Senate Testimony on S. 2172).

[69] *Tribal Contract Support Cost Amendments of 2004: Hearing on S. 2172 before the Senate Committee on Indian Affairs*, 108th Cong. (2004) (testimony of Lloyd B. Miller, Sonosky, Chambers, Sachse, Miler & Munson, LLP).

[70] Ibid.

[71] Tribal Contract Support Costs Technical Amendments of 2004, S. 2172, 108th Cong. (2004).

[72] *Id.* § 3(e).

[73] Cherokee Health Services, "Background Paper on Contract Support Costs," p. 2. *See also* Grim Senate Testimony on S. 2172.

[74] Grim Senate Testimony on S. 2172, p. 4.

available for the purchase of health care services. Likewise, each of the acts discussed above has the potential to provide notable improvement over a wide range of issues affecting Native American health care, regardless of their relative differences. Some of the issues addressed by these bills, by their nature, require legislative action for effective change. For others, though legislative action would be preferred, administrative action at either the department or agency level would enhance the process.

Conclusion

That change will come over the next few years to the Native American health care system is almost certain. The enthusiasm with which the current director has embraced the IHS mission, the general success of the continuing transition to tribal compacting and contracting, and the general sense that momentum in support of IHCIA makes passage in some form highly likely all portend change. The Commission has found that most of this change propels IHS on the path to improved health status for Native Americans. Yet, among the proposed changes the Commission has found reason for caution. Therefore, the Commission makes the following recommendations concerning the Indian Health Care Improvement Act and other pending legislative proposals that would positively affect the health status and outcomes of Native Americans:

- Congress should make passage of the Indian Health Care Improvement Act a priority item on the legislative agenda. The most recent version of IHCIA expired in 2001 and should be reauthorized.

- Congress should include in the reauthorization legislation of the Indian Health Care Improvement Act the 100 percent FMAP provision and the waiver of the penalty for late payment of Medicare premiums provision. These provisions were previously deleted but are necessary to increase the enrollment of Native Americans in public insurance programs and to amplify the resources available to provide health care services to Native Americans.

- Congress should make passage of the Tribal Contract Support Costs Technical Amendments of 2004, or similar legislation ensuring that contract support costs are paid in full, a priority item on the legislative agenda. Appropriate language should be included to reflect that additional funding should be appropriated without reducing the Native American health care budget in other areas. The refusal to fully fund contract support costs forces tribes to reduce spending on direct care services so that administrative expenses will be covered. Passage of this legislation will eliminate this practice and allow tribes to spend their entire direct care allotment on patient services.

- Congress should make passage of the Health Care Equality and Accountability Act and the Closing the Health Care Gap Act, a priority item on the legislative agenda. Passage of either of these proposals would accomplish many of the same objectives as IHCIA, but on a broader scale. Specific benefits include a mandate for additional funding, improved data management, and a greater emphasis on behavioral and preventive services.

In addition to congressional action, the Indian Health Service has a strong role to play in engaging tribes and undertaking measures to make tribes more effective at participating in

consultations related to pending legislative proposals that affect Native American health. Therefore, the Commission makes the follow recommendations:

- The IHS should conduct tribal consultation on the impact of the applicable provisions of the Health Care Equality and Accountability Act and the Closing the Health Care Gap Act.

- The IHS should form a working group to resolve the issues associated with Qualified Indian Health Programs, with an eye toward legislation to follow the enactment of IHCIA.

Chapter 6: Findings and Recommendations

Based on the review and examination conducted by the Commission, the two most striking characteristics of the Native American health care system created by the federal government are the use of limited and incremental responses to the health care challenges faced by Native Americans, and the fact that the health status of Native Americans continues to lag behind that of all other Americans. Native Americans die at an earlier age than other ethnic groups and their quality of life is diminished as a result of the prevalence of disease.

Treaties and related court decisions form the foundation of the federal government's undisputed responsibility to provide adequate health care to Native Americans. Congress has formally acted upon that responsibility on more than one occasion, and virtually every political leader addressing Native American health care has recognized this responsibility. This report evaluates the extent to which rhetoric is matched by action specifically aimed at improving the delivery of health services and the overall health status of Native Americans. Regrettably, the Commission concludes that our nation's lengthy history of discrimination against Native Americans, by way of unfulfilled promises, repeats itself as evidenced by the failure of Congress to provide the resources necessary for the creation and maintenance of an effective health system for Native Americans. The pattern of unfulfilled promises is also evident in the existence of cultural, social, and structural barriers that continue to limit Native American access to health care.

Unlike our earlier report on the quiet crisis created by unmet funding needs in Indian Country, this report looks beyond financing to examine other factors contributing to the disparities in health status and health care experienced by Native Americans. Based on this review, the Commission makes specific recommendations for improving the Indian health system. Generally, the recommendations of the Commission address the social, cultural, structural, and financial barriers limiting access to health care by Native Americans and adversely affecting their overall health status. The recommendations address a range of issues in each category including, but not limited to, educating and training health care providers and patients, recruiting and retaining health care providers, program monitoring and evaluation, and data collection. The recommendations also call for the passage of pending legislation intended to improve Native American access to health care.

Social and Cultural Barriers That Limit Native American Access to Health Care and Contribute to Health Disparities

It is true that individual social and cultural characteristics, most notably race, affect the quality of health care received in this country. The Commission finds that this is especially true for Native Americans who must navigate a health care system often insensitive to their unique cultures, who encounter health care workers biased against them as a people, and who suffer from disproportionate poverty and low levels of education. The Commission also finds that the Indian Health Service (IHS), as an advocate for and provider of Indian health services, has not

always been effective at reducing or eliminating the barriers identified in this report. Therefore, the Commission makes the following recommendations:

1. The IHS should create separate complaint processing offices within each IHS facility to monitor, investigate, and resolve complaints alleging bias and discrimination in either IHS facilities or contract health facilities. These offices should report directly to senior management.

2. The IHS should establish formal review and appeals procedures at the area office level and in headquarters to ensure timely resolution of all discrimination complaints and prompt notification to complainants regarding the status of their complaints.

3. The IHS, upon creation of its complaint processing offices, should require each office to produce periodic reports summarizing the number of complaints, the nature of the complaints received, and any remedial action taken. Based on analysis of these reports, IHS should formulate appropriate training programs aimed at eliminating bias and discrimination.

4. The IHS should implement formal cultural training programs aimed at teaching providers to present culturally specific health information and provide culturally appropriate services.

5. The IHS should implement cultural training programs for non-IHS providers at contract health facilities.

6. The IHS should, in addition to providing cultural training, expand efforts to hire more Native American providers who can better understand and communicate with Native American patients.

7. The IHS and other federal agencies, working in partnership together, should create and implement economic development strategies aimed at increasing tribal economic opportunities. These strategies should be tailored to meet the needs of each individual tribe, as identified through tribal consultations and sound research.

8. The IHS should involve Native American communities in collecting and monitoring community health data by partnering Native American communities and tribes with researchers, colleges, universities, and others with technical expertise in health research or Indian health research, in particular.

9. The Department of Health and Human Services (HHS) should increase the availability of grants to Native American communities for conducting health research and data collection.

10. The IHS should create and implement a formal policy to ensure that adequate professional language assistance is available at all IHS and non-IHS contract facilities, such as the use of call centers where IHS can provide and direct telephone language translation services.

11. The IHS should create and make available health information brochures in English and local native languages. These brochures should be distributed through IHS service units.

Structural Barriers That Limit Native American Access to Health Care and Contribute to Health Disparities

Independent of cultural and social characteristics, many Native Americans receive inadequate care as a result of structural obstacles. The Commission finds high staff turnover, and the resulting loss of continuity of care, particularly disturbing. In addition, many Native Americans must travel long distances to receive even primary care, patients must endure lengthy waiting times upon arrival, and many health facilities are outdated and in need of modernization. Furthermore, the Commission is aware of situations made worse by eligibility rules that close the door to care entirely. Accordingly, to address these and other structural barriers to health care, the Commission makes the following recommendations:

12. The IHS should re-evaluate its current Contract Health Services (CHS) eligibility requirement and adopt an eligibility requirement that allows all qualified Native Americans from federally recognized tribes to receive CHS regardless of their place of residence. The change in the eligibility requirement should come with an appropriate increase in funding to ensure that the resulting growth in CHS user population does not further weigh down an already overburdened system.

13. The IHS should provide technical training and assistance to Native American tribes lacking the resources and capacity to meaningfully and effectively participate in consultations with IHS.

14. The IHS should routinely assess and evaluate its tribal consultation and participation processes. In addition, the effective use of tribal consultation should be made a critical element in the annual performance evaluation of IHS managers to ensure that IHS managers are providing tribes meaningful and effective participation in all decision-making processes that affect Native American health care.

15. The IHS should standardize and coordinate its data collection efforts with tribes participating in self-governance contracts or compacts to ensure that comprehensive Native American health data are collected. The collection procedures and criteria adopted by IHS should be established in consultation with tribes. Standardized and coordinated data collection will make for more informed Indian health policies and initiatives.

16. The IHS should accelerate efforts to make telemedicine widely available and easily accessible for communities in remote areas. The IHS telemedicine programs should be carefully tailored to overcome challenges related to the lack of affordable telecommunications in some areas, reluctance on the part of service providers to utilize telemedicine technology, and concerns about providing culturally sensitive health services.

17. The IHS should redesign operating policies to reflect the reality that many Native Americans have limited access to reliable transportation and, as a result, have limited access to IHS health facilities. To address this problem, IHS should use more "walk-in" services, allowing walk-in appointments as part of its regular health delivery system.

18. The IHS should implement initiatives to reduce wait times at its facilities. These initiatives should include redesigning or reconfiguring waiting areas and examining rooms to reduce overcrowding and increase productivity and efficiency, hiring more staff to reduce workload, training staff on time management, and increasing productivity and efficiency.

19. The IHS should revise its recruiting and retention programs and take proactive measures to recruit and retain qualified providers. The revised IHS recruitment and retention programs should include tailoring the programs to meet the specific recruiting and retention needs of various IHS Service Areas by providing competitive pay to providers in areas where parity in pay is an issue, providing adequate housing or supplementing housing costs to address lack of adequate housing, and providing special incentives for providers in rural areas to compensate and address the lack of lifestyle choices in rural areas.

20. The IHS facilities should be properly equipped with screening and diagnostic equipment to provide early detection of disease. Early detection will reduce mortality rates and medical costs over the long term. In addition to screening and diagnostic equipment, adequate training for providers must be provided.

Financial Barriers that Limit Native American Access to Health Care and Contribute to Health Disparities

Virtually any examination of existing health disparities experienced by Native Americans must include an examination of funding. This report is no exception. The Commission finds that current funding levels are insufficient to operate an adequate health care system for Native Americans. The Commission further finds that the degree of underfunding is most extreme for urban Indian health programs and contract health services.

Many of the funding barriers are found in the fine print of confusing administrative regulations. To the extent these regulations create unnecessary obstacles, they must be modified or, when appropriate, completely eliminated. Accordingly, the Commission makes the following recommendations:

21. Congress should raise funding levels to reduce the national average FEHBP Disparity Index (FDI) from the current 52 percent to 80 percent. No federally funded program providing health care to Native Americans should be permitted to fall below an FDI of 60 percent. In the long term, Congress should raise funding levels to establish an average FDI of 100 percent.

22. Congress, in all future IHS appropriations, should ensure that the IHS budget is adequate, independent of any consideration of increased third-party collections. In

addition, Congress should include language in IHS appropriations specifically reaffirming that increases in third-party collections are not considered in determining IHS funding levels.

23. Congress should establish a high-level investigative body to study changing Native American health care to an entitlement. This investigative body would also create a mechanism whereby the provision of health services to Native Americans by the federal government becomes mandatory and enforceable. This investigative body must include representatives from tribal and Indian advocacy organizations.

24. Congress should immediately appropriate special funds for contract health services to a level sufficient to eliminate the rationing of health services for Priority I patients. The IHS, in consultation with tribal representatives, should establish this funding level and all future IHS appropriations must be justified with reference to this new, higher figure.

25. Congress should immediately appropriate special funds for urban Indian programs to enable the establishment of programs capable of providing care at the level of reservation Indians. In more specific terms, the Commission recommends increasing appropriations by an amount equal to the per capita expenditures for current IHS users (as modified by the above recommendations) multiplied by the number of anticipated urban Indian program users. Future appropriations should be justified with reference to this new, higher figure.

26. Congress should establish a mechanism to ensure that contract support costs are fully funded on an annual basis.

27. Congress should enact legislation, similar to that in the proposed Indian Health Care Improvement Act, linking the 100 percent FMAP reimbursement to the individual patient, rather than the facility used.

28. Congress should establish a mechanism to ensure that future appropriations track with inflation.

29. Congress should consider indexing increases in IHS appropriations so that, at a minimum, IHS program increases keep pace with increases in Medicaid and Medicare programs.

30. The IHS should investigate mechanisms to allow increased decision-making authority at the tribal, area, and service unit level, particularly with respect to minor facilities modifications.

31. The IHS should update the unmet need methodology to reflect more recent data on enrollment in private and public insurance programs, particularly in light of the identified discrepancies with the 25 percent third-party recovery figure.

32. The IHS should develop an improved public education and outreach program to establish eligibility and facilitate enrollment in public health insurance programs, in order to maximize collection from alternate sources. Any efforts should incorporate the

best practices from tribal programs with significant increases in third-party collections, including one-to-one interaction and oral communication modes.

33. The IHS should improve its existing internal staff training efforts on the administration of public health insurance programs. Participation in such programs should be mandatory and ongoing for all staff responsible for managing, supervising, or advising Native Americans on eligibility and enrollment in public health insurance programs and for those involved in IHS third-party collection efforts.

34. The IHS should establish measurable goals and timelines for increasing enrollment in public health insurance programs.

35. The IHS should evaluate the current data management system and evaluate options for implementing a modernized health data system.

36. The IHS should study the impact of creating a mechanism that would enable appropriated funds to be spent on urban Indians outside Title V programs.

37. The IHS should evaluate its method for using historic cost data in its negotiation of all-inclusive rates, with an eye towards using more current cost-report data. Alternatively, IHS should develop a mechanism, whereby adjustments can be made to reflect actual cost rates at time of service.

38. The IHS should evaluate the current Indian Health Care Improvement Fund (IHCIF) program, with an eye toward developing an alternative that can provide a more realistic approach to resolving inequities between the various tribal programs.

39. The IHS should monitor the third-party recovery efforts of individual IHS facilities and take corrective action to raise collections in delinquent programs.

40. The Centers for Medicare & Medicaid Services (CMS) and IHS should evaluate the current Medicare/Medicaid reimbursement mechanisms available to Native Americans, with an eye toward establishing a program, combining elements of the Qualified Indian Health Program and critical access facility programs proposed in the Indian Health Care Improvement Act (IHCIA) and interagency agreements, that will enable full and adequate recovery, while operating within the confines of the present and anticipated IHS data systems.

41. The CMS should encourage state Medicaid programs to participate in the Medicaid Administrative Matching program, particularly with regard to Native American programs.

42. The CMS should encourage state Medicaid programs to provide state representatives in IHS and tribal facilities, utilizing the Medicaid Administrative Matching program where applicable. If necessary, CMS should incorporate additional incentives.

43. The CMS should consider modifying its six-month re-determination requirement for Medicaid and State Children's Health Insurance Program eligibility.

44. The CMS should re-evaluate its decision with respect to Native American waivers in state-operated CMS programs, in light of the unique political status of Native Americans. The CMS should encourage state Medicaid programs to establish waivers similar in effect to the 100 percent FMAP program.

45. The CMS should evaluate the feasibility of providing equitable relief for those elderly Native Americans who, as a result of federal programs and policies, fail to qualify for Medicare under the 40-quarter requirement. Specifically, equitable relief should establish enrollment eligibility for those Native Americans who otherwise fail to qualify for Medicare as a result of government policies. This equitable relief could be similar in form to that provided to those Native Americans who failed to enroll in Medicare as a result of faulty enrollment guidance. In those circumstances, relief has been provided by granting waivers from the surcharge for late enrollment in Medicare Part B.

46. The CMS should conduct an evaluation of the sufficiency of federal regulations governing administration of Medicaid and Medicare programs by IHS and tribal facilities, to ensure that administrative guidance is consistent and fully developed.

Proposed Legislative Changes Affecting Native American Health Care

In the past several years, substantial effort has been expended to identify technical changes that will improve the system providing health care to Native Americans. As a result, a number of finished proposals await implementation. Foremost among those proposals is the reauthorization of the Indian Health Care Improvement Act. The Commission supports the reauthorization of IHCIA. The Commission also finds that other legislative initiatives, though not as broadly applicable to improving the current system, also contain seeds of hope for Native Americans. Accordingly, the Commission makes the following recommendations:

47. Congress should make passage of IHCIA a priority item on the legislative agenda. The most recent version of IHCIA expired in 2001 and should be reauthorized.

48. Congress should include in the reauthorization legislation of IHCIA the 100 percent FMAP provision and the waiver of the penalty for late payment of Medicare premiums provision. These provisions were previously deleted but are necessary to increase the enrollment of Native Americans in public insurance programs and to amplify the resources available to provide health care services to Native Americans.

49. Congress should make passage of the Tribal Contract Support Costs Technical Amendments of 2004, or similar legislation ensuring that contract support costs are paid in full, a priority item on the legislative agenda. Appropriate language should be included to reflect that additional funding should be appropriated without reducing the Native American health care budget in other areas. The refusal to fully fund contract support costs forces tribes to reduce spending on direct care services so that administrative expenses will be covered. Passage of this legislation will eliminate this practice and allow tribes to spend their entire direct care allotment on patient services.

50. Congress should make passage of the Health Care Equality and Accountability Act and the Closing the Health Care Gap Act a priority item on the legislative agenda. Passage of either of these proposals would accomplish many of the same objectives as IHCIA, but on a broader scale. Specific benefits include a mandate for additional funding, improved data management, and a greater emphasis on behavioral and preventive services.

51. The IHS should conduct tribal consultation on the impact of the applicable provisions of the Health Care Equality and Accountability Act and the Closing the Health Care Gap Act.

52. The IHS should form a working group to resolve the issues associated with Qualified Indian Health Programs, with an eye toward legislation to follow the enactment of IHCIA.